UNIVERSITY OF OSLO
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Developing health information mash ups system for thoracic surgery patients: A patient - participatory design study

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Content list

List of figures

ABSTRACT

The contribution of this study aims to support patients during the thoracic surgery trajectory at Oslo university hospital. It does so by developing a health information mash up prototype, similar to the technology called patient health record system (PHR). The prototype includes access to information such as medical record contents and standard patient information. In addition, the system facilitates the exchange of information between patients and healthcare providers, by providing accurate and timely information, e.g. web form for the patient own report ahead of surgery, adjusted standard patient information sent to the patient ahead of consultation, access to social networks and secure communication with healthcare provider with more. The proposed PHR could be viewed in the light of the research field Computer Supported Co-operative Work (CSCW). Two volunteer former patients have shared their patient stories and participated in an in-depth case study. Furthermore, the gathered data has been structured into actions to identify situations where the participants themselves have actively taken the initiative to get information, based on different motives like decision making, mental preparedness, knowledge, and more. These activities are analysed applying concepts from the Cultural Historical Activity theory (CHAT), as well as components from Yjro Engeström's activity system model. The use of CHAT to understand the social and technical aspects of the patients' work and information need has been helpful in informing the system design process. The identified and mapped patient activities during the thoracic surgery trajectory were evaluated by the participants in a final follow up interview. The main objective within the design project was to develop health information visualizations that participants found useful. The participants contributed in the experimental design process, based on their knowledge and patient experiences. The design project has resulted in organizing relevant patient information both in timeline views, and in a prototype of an interoperable web based PHR for thoracic surgery patients called Thoraxpasient.com.

PREFACE

The Interventional Centre (IVS) at Oslo University hospital HE, Rikshospitalet has initiated a project to develop a thesaurus for thoracic surgery patients, for access of own medical record during hospitalization. The application is designed in a way that makes it possible to look up medical terms used in medical records that are accessed via DocuLive. It works as a medical translator for laypersons. In this context, the IVS collaborate with personnel at the Thoracic Surgery department in developing and expanding the medical translator, to include common medical jargon related to thoracic surgery domain. Parallel with this project, IVS researchers advertised for students that where interested in graphical user interface and design in a personal adaptation to the patient health record system (PHR or like patient portals). I was given the opportunity to perform an independent investigation on how to approach the design of IT support for patients accessing own health records. In the current project pre- and post surgical patients was invited to take part in the design process, so as to assess the information needs of patients during their thoracic surgery process.

I am grateful to my super adviser at IVC, Laura Slaughter, who has provided me with the opportunity to work on this thesis, and guided me firmly through it. Her patience, knowledge and skills have been invaluable sources of inspiration. Furthermore, I thank my co-advisor Tone Bratteteig, for her unfaltering support and many suggestions. Also, Tone's lectures on 'Computer Supported Cooperative Work' (CSCW) opened my door to social theories applied in computer sciences, including activity theory. I would also like to thank Leif Helland for thorough proofreading the report. Finally I would like to thank the two study participators, whose contributions made this study possible. They generously shared own personal stories and scarce time, with a vision and hope that their stories and patient experiences might help others. I am deeply grateful for your contributions!

Anita Woll, 01/02/2011

1. INTRODUCTION

The organization of the healthcare system in Norway includes patients traversing several healthcare providers and institutions during comprehensive patient trajectories. Often patients experience lack of information as well as inefficient coordination of care, as they move within trajectories of fragmented healthcare services. This study investigates how a specific patient group traverse several health institutions in search of necessary health information. Two problems stand at the centre of the analysis: (1) What health information activities does patients undertake during the thoracic surgery trajectory? (2) How should new technology be designed to support patients health information activities throughout the thoracic surgery trajectory? In answering these questions I hope to contribute to a better understanding of the social and technical aspects related to thoracic surgery patients, in relationship to a future health information mash up system for that specific patient group. The outcome of the study is to develop a prototype of new technology which aims to support the thoracic surgery patients, as they traverse the thoracic surgery trajectory.

My main contribution is the study of social and technical aspects to PHR for potential users within the thoracic surgery healthcare context. The social aspects involve studying how participants perform health information activities within the thoracic surgery trajectory. I have gathered information about health information activities through informal and formal interviews of two participants. Both respondents have performed an aortic valve replacement at Oslo University hospital - Rikshospitalet. The cultural historical activity theory (CHAT) is applied in the analysis, with intentional patient activities as units of analysis. The version of CHAT used is the one proposed and extended one by Yjro Engeström (2000, 2001), also referred to as the third generation of CHAT. I have supplemented Engeström (2000, 2001) by also including intentionality, original information source and design consideration. Every intentional health information activity recalled by the participants' memories is restructured by the components in the activity system model, including subject, tool, object, division of labour, community and laws. All in all, 24 activities is identified and applied as background material in this study. In addition, concepts from Anselm Strauss and co-authors (1982) is applied, including the concept of trajectory work and patient work during regular patients activities. By use of a sketched flow chart of the standard thoracic surgery trajectory, I manage to identify activities by each participant. These are mapped into the chart, and sorted

by type of information source. The localization of the activity is organized by use of timeline, illustrating the different phases as initial “time” units within the trajectory. Thus, the identified activities are limited to the time period of the thoracic surgery process. Furthermore, I draw a selection of three activities as activity system models, to emphasize identified problematic trajectory and information gaps within the activity system. In addition I use one other concept from the CHAT; the cultural historical review of the mediating tool. For this purpose, I have reviewed the medical record from its initial appearance and up to recent time.

The technical approach includes studying how new technology should be designed to support participants in their health information activities throughout the thoracic surgery trajectory. Technical aspects are investigated by a concise literature review, and design considerations based on findings in the case studies that include use, interaction, and design of PHR technology with primary focus on information visualization. Prior authentic thoracic surgery patients have participated during development, experimental design and trial implementation. The outcome of the study is a proposed prototype of a PHR for thoracic surgery patients, designed after system requirements indirectly set by the participants. The prototype with its core features is implemented as a web based PHR, called “*Thoraxpasient*” (http://www.thoraxpasient.com). *Thoraxpasient* is a website that provides user access to a fake medical record set; a timeline for overview of medical records with standard patient information structured in views for different phases included in the thoracic surgery trajectory; optional additional timelines for administration of specific objects (e.g. medication, home monitoring tests); comment options for own notes to medical record; options for use of dictionary for medical terminologies; reminders of patient-rights (e.g. covered physiotherapy the coming half year after rehabilitation stay); mail box for communication with healthcare providers; a calendar for management of scheduled follow ups with more. The standard patient information should also be designed with print option to paper-based format, to be accessible for patients also during hospitalization (when Internet access may not be available).

Having introduced the problem situation and own contribution. I now turn to the motivation behind the study.

1.1 Motivation

Surgeons working in the thoracic surgery department at Oslo university hospital – Rikshospitalet Interventional centre have expressed a need to support patients who desire to read and use their medical records related to surgery. The surgeons recognize that currently patients do have access to their own records, while at the same time lack technology support, especially for complicated and problematic illness trajectories (e.g. involving multiple surgeries). In medical informatics, what the surgeons were suggesting overlaps with what is commonly called "patient portals", or "personal health record (PHR) systems" (Tran, Zhang, Stoylar & Lober, 2005). Currently a number of different models, and sub variants of PHRs are offered to regular patients for management of health in a life perspective, or to more specific patient groups such as victims of public health outbreaks (e.g. influenza pandemic); elderly people; and the chronically ill (e.g. diabetes or bleeders, mother – child program during pregnancies, cancer, or patients belonging to a specific healthcare institution with others). None of these PHR systems concern patients that undergo surgery, with their health information need during the surgery process. In addition, none of these systems described in scientific papers have a methodological approach that ends up recommending a framework that can make a constructive contribution in informing the system design process. Nevertheless, the literature reviewed habitually contains statements of the importance of including users during the design, development and testing of PHR. Furthermore, existing systems that display the contents of medical records in a useable way, are often developed primarily for healthcare workers, with the cooperation of what can be considered as highly informed and technically savvy users. Plaisant´s Lifelines work within the area of information visualization is one example. The design of his interface was tested on computer science students, which were able to effectively use a display that organized health events along a timeline (Plaisant, Milash, Rose, Widoff & Shneiderman, 1996). A literature search within medical informatics and the field of human-computer interaction reveals little understanding of how information seeking and use takes place within the complex healthcare system that patients must navigate. Nor does it reveal an understanding of how to translate this into useful design suggestions for a patient-oriented information system.

Today patients have become active participants in own health care management together with their healthcare providers. Thus, patients are well aware of their legal rights as conscious health care consumers, and are commonly included in decisions making regarding own health issues. Healthcare providers are under a pressure to deliver healthcare to patients in a cost –

effective manner. They may profit from active and empowered patients in their search for effective solutions. Thus, patients and healthcare may both benefit from new technologies in support of patient healthcare management. The users of future PHR systems are considered to be thoracic surgery patients and their healthcare providers (likely to be the patient coordinator). The patients that are granted user access are persons either living with heart illness that are under assessment for thoracic surgery, or patients that already have received thoracic surgery. In addition, healthcare providers are indirect users of the information system. They might not have own user profiles, but they are assumed to be interacting with the technology by adding standard patient information to the information system. Medical records are produced by the healthcare providers as they coordinate and report the healthcare service provided to each patient under treatment. Likewise, the healthcare provider could contribute with professional feedback in social network included in PHR. One may perhaps view the role of the healthcare providers as that of a banker in online banking. Still, the healthcare provider's interaction would be more frequently and timely than that of a banker.

To apply the fully user benefits and potentials to the prototype of an information system, persons already suspected to be candidates for thoracic surgery in the future, or persons in initial phase of this trajectory should be given access. Thus, the vision of the information system is to support patients with information and features for use and re-use of accessible health information during the time period for which they are in the thoracic surgery trajectory. However, sharing medical record access and relevant health information between patients and healthcare providers offers a number of challenges. Computer scientists have designed and implemented medical health record systems (EHR) for healthcare providers for decades. It is clear that a user interface to medical record for patient is highly achievable. What is lacking is technical standardizations and legal regulations. As a consequence, PHR technology have primarily resulted purely theoretical PHR systems, or trial PHR systems that have been made accessible only to a limited number of users, but which in the future promise extensions that include access for all users to aggregated electronic medical records from patients' healthcare providers' EHR systems. Additionally, the EHR documentation accessible contains a summary record content (SRC), that health providers may access in emergency or in unscheduled health care situation. The collection of electronic medical documentation is often compared with online banking technology, where electronic documentation of received health care services is timely and accurately accessible for the purchaser. For this reason some PHR vendors refer to the technology as Health banking. However, just accessing a detailed

"health receipt" or patient summary from a given health care service may not be very helpful by itself. The written information can be difficult to understand, given that doctors use medical terminologies. In addition the content needs to be put in a context of meaning to past, current or future patient trajectories to make sense for the patient. E.g. patients experience in current information flow between different healthcare institutions they traverse through during the thoracic surgery trajectory. Each institution has a special concern for the patient during his/her stay. Still, they lack knowledge about healthcare services performed at other institutions included in the patient trajectory. Thus, fragmented healthcare services result in fragmented health information. Patients need more than just shared access to medical records by her/his healthcare provider(s). They need an information system that can glue together the fragmented health information pieces, to a complete information trajectory package. Such an information system has to include both medical record content and standard patient information, in order to support the patients in initial entry-, during- and after the trajectory. The medical record content is often written in retrospective time, and therefore informs patients about what happened in the past. While the standard patient information is prospective information that informs patients about what will happen during the whole trajectory. Design of such information system will hopefully enable patients to use / re-use information further, e.g. for gaining insight into own health; mental preparedness; knowledge; decision-making; and to inform future healthcare providers with accurate required information; and more. Giving thoracic surgery patients access to such tools, will empower them, and make them better equipped to engage in their own health and cooperative work together with their healthcare providers. In addition, use of PHR could ease pressure on scarce healthcare resources, and might reduce the in-person visits to the healthcare provider if the system is design in a way that is satisfactory for the patients. Furthermore, the system could support the patients in situation when they need information, and for some reason the information needed is unavailable to them. The contribution in this thesis is hopefully to initiate PHR for thorax surgery patients that will benefit the interrelationship in collaborative work, and make the thoracic surgery process more efficient for both patient and healthcare providers.

2. BACKGROUND

In chapter two, I first describe different aspect of the PHR technology, following potential users of the new technology. Secondly, the work of Anselm Strauss is briefly summarized,

including his recognition of patients doing work and patient trajectory. Next follows a section describing the placement of the design study relative to Computer Supported Co-operative Work (CSCW). Fourth, prior studies of healthcare that follows the cultural and historical review of the medical record is discussed. Lastly, I discuss the mixture of methodologies used in this study, including the theory of action and the cultural historical activity theory together (CHAT).

2.1 State of the art

A personal health record (PHR) is based on the principle that patients have a right to own and manage copies of their medical information. Its main functionality is therefore storage of individual's personal health information. In Norway patients have the legal right to access their own medical records (Pasientrettighetsloven § 5 –1). This right is frequently used as a consequence of the increased focus on user-oriented health services. South-eastern Norway Regional Health Authority has made a contract with their regional hospitals. Under this contract the hospital should offer discharge summery to every patient on discharge after hospitalization (South-Eastern Norway Regional Health Authority, 2006). Patients are invited and expected to involve themselves in decision-making concerning their health. For this reason they have a greater need for information at hand, in order for them to participate and collaborate with their doctor. In recent years, deficient communication between the patient and provider has gotten attention, especially with respect to patients with severe diseases (Faulkner, 1998). The positive feedback from the patients included in the trial project of "Discharge summary in hand" is motivating for further work, and for alternative ways of access and presentation of medical information to the patients (South-Eastern Norway Regional Health Authority, 2006). Several health providers wish to give the patients the discharge summary in electronic format. This opens up the opportunity for adding support tools with the discharge summary, for example a web based PHR portal. The reason being that the patient–provider relationship is constrained by a lack of understanding of the medical jargon expressed by doctors and by the limited time doctors can allocate to each patient. Patient-centered health care require efforts from both patient and provider. The question is how can the information exchange be organized in ways that are satisfactory for both parties? Nückles, Wittwer and Renkl (2005) claim that to attain an effective and efficient guidance to laypersons, professionals have to adapt their explanations to the typical laypersons level of knowledge. One way to improve upon this situation is to extend the PHR system with tools that make the medical record more helpful and user-friendly to the layperson. In this context

the PHRs may perhaps contribute to transformational changes in health care delivery, and give the patient and provider more of a shared responsibility for health care (Detmer D, Bloomrosen M, Raymond B & Tang P, 2008).

It is important to note that the PHR system is designed for the patients, and that it should not be confused with electronic health record (EHR) that is the "*longitudinal electronic record of patients health information generated by one or more encounters in any care delivery setting*" (Healthcare Information and Management Systems Society). Nonetheless, the EHR plays an important role in the PHR system, since the medical record is produced and further utilized in the physicians EHR system. The majority of health enterprises in Norway are using EHR as a tool to support health care providers in their work. However, the EHR systems in Norway are fragmented systems[1], and synchronizing these systems into a shared interface is not an easy task. If a patient today is gathering copies of own medical records for a paper-based PHR, s/he has to contact each hospital visited, the general physicians, and health and social services used, to manually get copies, since the health enterprises are largely using different EHR systems which are not inter-operable.

The term PHR derives from the low-technology solutions where health consumers started to collect and keep paper- based health documents privately. At some point consumers started to enter this information into computers where they could organize the information using spreadsheets and word processing programs. From here the system evolved into many platform-types (see table 1) and models. In this paragraph I will describe 3 prominent PHR models.

1 There is not a shared EHR system in the health care service in Norway. For example Infomedix and DIPS are often introduced in local hospitals, while DocuLive is more frequent found in regional hospitals. The generel physicians have other systems like Infodoc, Profdoc, Legenett with more. However, the Norwegian health enterprises are working to get a shared national EHR in the health care service.

Model	Portal	Storage device
Paper-based PHR	Paper	Binders, boxes
PC-based PHR	PC	PC-based software
Web based PHR	Internet	Remote server
Mobile Smart phone based PHR	Mobile phone	Personal mobile Smart Phone based application
Portable storage PHR	PC	Memory stick, CD, DVD, smart card, smart Phones

Figure 1: Overview of type of PHR models, portals and storage device

The free-standing PHR model is paper-based, PC-based or Internet-based PHR that is populated and updated by the user's manual data entry. The standalone PHR model is not integrated with the provider's EHR system. This model allow patients to administer and store health information manually, either directly by the patients themselves or indirectly using of mass storage device like CD-ROMs, memory sticks, or smart cards and the like. The PHR is a patient owned and patient controlled PHR. The system is accessible anywhere, and could be viewed by the patient's provider. Examples of this model are Google Health and Microsoft Health Vault that are both standalone. The drawback with this system is that the quality of the PHR content is left to the patient in its entirety, so the provider has to trust the patient for its completeness. Another disadvantage of this system is the vulnerability for destruction and physical loss of medical documentation, pc and mass device storage. The integrated (also called interconnected or networked web-based) PHR model is an Internet-based PHR[2] that is integrated with several providers like the physician's EHR, hospital's EHR, pharmacy's prescription registry, and insurance company, and more. Tang and Lee (2009) define an integrated PHR as an extension of the physicians' electronic health record. As such, this system is a tool for both patient and provider, since the provider EHR is supplemented with contributions from the patient entered in assigned areas in the EHR. The system is accessed via the Internet. This model is a shared patient – provider controlled and owned PHR, where the healthcare provider has influence on the information quality. Compared to the standalone PHR, this model may reduce the re-entry of health information, and thereby reduce error typing and duplications. In addition, since both patient and provider are contributors to the

2 The integrated PHR is accessed with an Internet portal, but in addition this system in some cases requires PC-based software, for example software like personal certificate for secure log in or tools for additional PHR support with more.

PHR it may make the health information more complete. Tethered PHR (also called institution-specific) model is an Internet-based PHR that is integrated to a specific provider's EHR, where the patient can access part of their own records. This model constitutes a limited version of the integrated PHR, since the patient only has access to a single provider's EHR. These systems offer largely additional functionality, like communication with the provider via secure email, request appointments and request prescriptions renewals, and more. The system is accessed via the Internet. This model is a clinical-controlled and clinical-owned PHR, with exceptional systems that to some degree allow patients to contribute into selected areas of the record.

'The most favourable model choice of PHR is the fully integrated model (Detmer, Bloomrosen, Raymond & Tang, 2008). There are several reasons for this. The integrated model is aggregating records from several providers and not just a specific provider like the tethered model. By doing so, the patient will have a complete collection of health information. Likewise, this model does not require manual feed and regular maintenance of information from the patient, and therefore the quality of PHR content is not dependent on the patient responsibility alone, as it is in the standalone PHR model. The integrated model is also favourable in that in serving both the patient and the provider, the health information registered in the providers EHR may be supplemented with contribution from the patients in assigned areas in the PHR. These patients' notes can be shared with the provider. An important precondition is, however, that the patient is not able to over-write, delete or change the content in the record copy sent from the provider. Such a restriction avoids ruining the quality and value of the original record. If the patient reveals errors in his or her record, the patient should go to the provider and correct the error to maintain updated and correct record content.

In addition to PHR models and platforms the PHR infrastructure refer to how the health information data is aggregated from one or multiple external data sources (GP, local hospital, regional hospital) to gather health information. Figure 2 displays a number of solutions to the PHR architecture for integrated or institution specific models, that are extracted from the literature dealing with excising or suggested PHR architectures.

PHR architecture	PHR description
Healthcare provider- tethered	Exchange information between the PHR and a specific data source (a single EHR source). Limit exchange of information from PHR to the EHR system.
Payer – tethered	Exchange information between the PHR and a specific data source (a single EHR source) Limit exchange of information from PHR to the EHR system.
Third – Party	Exchange information between the PHR and a third party, which are a repository of data sources, collected from multiple EHRs (Google Health, Microsoft Health Vault, Dossia platform) Limit exchange of information from PHR to the EHR system.
Interoperable	Exchange information between the PHR and the patient's data sources (multiple EHRs). The gold standard of the future where information exchange between PHR and EHR goes both ways and whereas the patient controls which information that the EHR system may import.

Figure 2: Overview of PHR architecture for health information exchange

The PHR architecture type called "interoperable" is set to be the gold standard of the future PHR, based on it flexible constructed nature, in which medical records from the all of the patient's healthcare providers can be accessible via the system. Today most PHRs or initial PHR trials available in the market are based on the tethered solution, whereas only medical records from a specific intuition's EHR are available for the health institution's patients. The third party solution may be an important approach while waiting for legal regulation to open up for the future interoperable PHR solution.

An investigation of content within the PHRs reveals that common health information and features often persist in several of these systems. The different PHRs are typically addressing different user group, but often contain a similar set of core information such as listed below.

Common PHR content
Past and current medical history
Next of a kin information
Immunization profile
Allergies / cave
Complete medication profile
Contact information to GP and specialist health care provider
Data log over professionals that have access patient's record
Lab tests
X-rays
Ultrasound picture
In addition to the PHRs core information, several other features are regularly included in PHRs, such as:
Vital details (height, weight, BMI)
Medication remainders
Diet advice
Training advice
Weight loss program
Diaries
Online booking system with providers
Online communication with health professionals (chat, web cam, e-mail)
Prescription renewals
Social networks related to own illness or problem

2.1.1 Scandinavia perspectives

The Norwegian parliament has by the Coordination Reform (St.mld. 47 (2008-2009)) acknowledged that online electronic communication between the patient and healthcare provider will be the regular way of communicating. In addition, the reform permits patients to

access their medical record electronically as well. The Coordination Reform also includes exchange of medical records between the patients' healthcare providers, across institutional boundaries and EHR systems. As a result, the possibly adverse consequence of too much health information exchange has recently been heavily debated. A common argument against health information coordination is the danger that persons with "wrong intention" could get access to sensitive information more easily. E.g. the possibility that close relatives or healthcare providers would seek sensitive information for curiosity alone, or the possibility that private institutions (such as insurance companies and the media) could access the medical records of individuals for commercial reasons. It is easy to understand that information available for a larger user group may increase the data vulnerability of the complex, fragmented and large information system that the EHRs are. Thus, making medical records available to a larger user group demands the establishment of new routines dealing with data security and technical standardizations, including smart solutions to prevent unauthorized persons to access sensitive information. The Data Inspectorate suggests that patients also should get access to the medical record log once a year for quality assurance of who has accessed the patient's medical record. However, it would be easier for patients to quality assure the medical record log by including it into the PHR technology. The log should contain information about who has access and the purpose behind the access (e.g. treatment, research, administration and more). This log feature might be an extra motivation for patients to actually adopt the PHR technology. The health authorities have already ordered several actors (see next section) to start working with potential solutions for secure online health information exchange.

The Norwegian Centre for Informatics in Health and Social care (KITH) has developed a standard for health care message exchange called 'hodemelding', with a supplementary application receipt (KITH, 2008). This is an important step in securing the different providers ability to securely share sensitive health information. Furthermore, this message exchange standardization also makes it possible for the health providers to send messages to a potential patient's PHR.

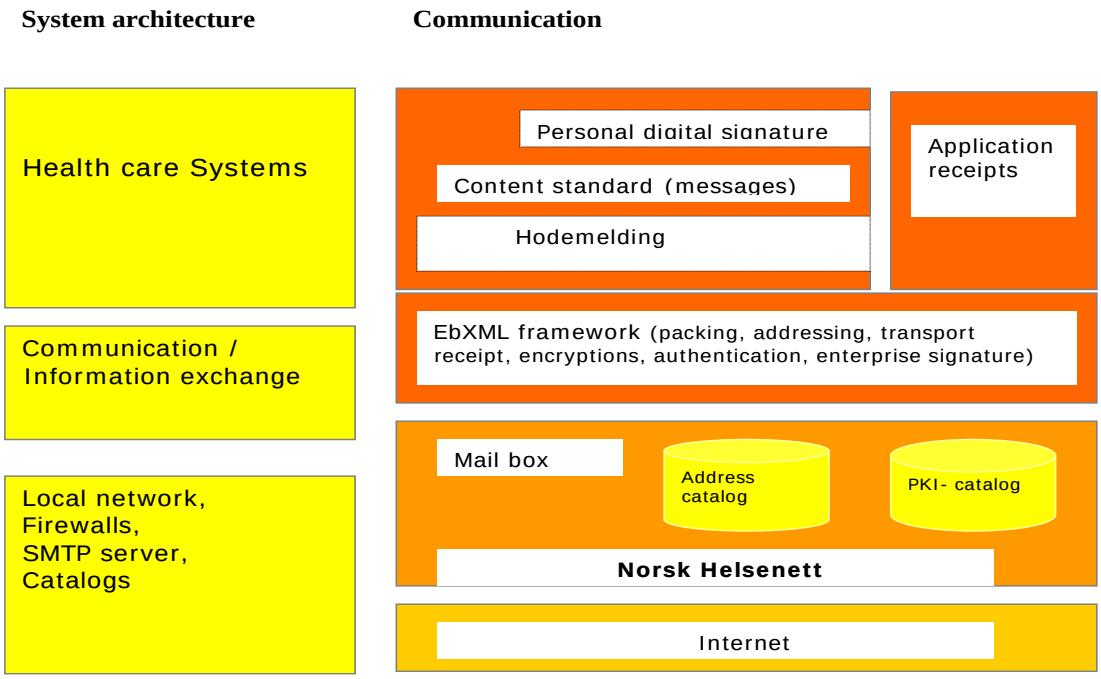


Figure 3: Overview of the system architecture and messages communication when using *Hodemelding* (Copyright & source: The Norwegian Directorate of Health, 2006)

This standard has been the required one for health information exchange since 2005 in Norway, and therefore has to be adapted to the PHR system. KITH sets the standardizations for several schemes and routines used in health care services and IT. For that reason their standardized documentation will be of great importance to this project. Figure 3 displays the system architecture and message communication when using 'hodemelding'. The content standard is an establish one for ensuring accurate content and structure of the included message text in the 'hodemelding'. The digital signature option is a new functionality introduced in the trial project of electronic prescription shipment between the doctor and pharmacy. The ebXML framework provides the necessary mechanisms to handle the information exchange between health care enterprises, and describes, among other things, mechanisms for security, as well as safe and reliable message exchange. The use of encryption and signature on activity level by use of Public Key Infrastructure (PKI) is for protection of information against changes and transparency. The ebXML business uses certificates to secure (using encryption and secure authentication) shipment between various parties. The Norwegian Health Network is a closed network for electronic communication and collaboration in the health and care sector in Norway. The Norwegian Health Network

offers e-post service that can be used for message communication. Information transferred through the Norwegian Health Network has to be encrypted before it is sent from a health care enterprise / unit. When a 'hodemelding' has reached the target address / receiver, the receiver automatically returns an application receipt. This receipt includes a confirmation about the ability to interpret the received message. If the receiver cannot interpret the message, the application receipt will give feedback on the likely cause of error.

The Coordination Reform has not included any plans or deadlines for implementation of a national PHR, but several trial projects have been initiated by various health enterprises. However, Norwegian laws (like the Privacy Protecting Act and the Health Law) are protecting patients with regard to nongovernmental actors offering PHR technology. E.g. electronic health information exchange has use the Norwegian Health Network, and all organized storage of personal information needs approval from the Data Inspectorate. Recently, the Health and Care Ministry of Norway has paid attention to the need for standardized patient trajectories regarding complex illness like cancer, addiction, and severe mental illnesses, to better coordinate information and care. This is explicitly formulated as a strategy for Health 2020. In this context, a PHR designed for patients during the thoracic surgery trajectory might be applicable to other types of patient trajectory.

A throughout selection of trial project and potential early bees PHRs in Norway is presented in the following sections, to look at possibilities and experiences done in a Norwegian context. As far as I am aware, the World Medical Card is the only standalone PHR system in Norway in which consumers may add medical record information for use in acute health situations. In 1998 a company in Bergen started developing an international smart card for access to personal medical records. This was done in collaboration with physicians and the University of Bergen. The smart card stores vital health data on an individual (see smart card figure 4). The consumers are required to enter the health information manually using an Internet based portal, and the consumers accordingly bear the full responsibility to keep the data timely and accurate. The smart card contains information about personal data, health condition, diagnoses, allergies, vaccinations, prescription drug record, next of kin contacts, donor requests and any medical contradiction. Diagnoses and drugs are listed using the ICD-10 standardization and ATC / DDD. The philosophy behind WMC is that an individual can carry essential medical information anytime and everywhere in the world. The individual, or the individual's provider, can access the emergency data by downloading the information to a

mobile phone, or, alternatively, by use of a special chip scanner or by cutting the card to access a sealed version of medical information. The mobile phone solution has a translation service that supports translations into 10 different languages; to meet the needs a consumer confront abroad.

Figure 4: The appearance of World Medical Card

Similar to the vision behind WMC, critical health information on an "accurate, updated and timely" basis has been a leading motivation for the development of a central server that store essential individual health information for use in acute situations. The system primarily target health providers that need this information when treating patients for which no record exist in their institution's EHR. The system is called the national Core Journal, and the Data Inspectorate has given approval to further development of this Norwegian version of so-called "patient summary". It seems safe to assume that the Core Journal will be an important brick in the future development of PHR in Norway. It is the Ministry of Health and Care service that has asked The Norwegian Directorate of Health to develop a national consent based Core Journal that is an ICT[3] based solution. Implementation of such system is set to 2013. The idea is that the health professionals should be able to access this information without contacting the patient's regular doctor or health enterprise. The Core Journal is not similar to a journal. Rather it is a collection of core information extracted from the electronic patient records (EHR). In Sweden they have a system like this, and call it a *patient overview*, which is probable a more descriptive name. By the time of writing, over 17 other countries in Europe are developing systems for the Patients Summary (The Norwegian Directorate of Health, 2009). The Core Journal works roughly like this: The regular general physicians (GPs) have the overall medical responsibility for their patients. If the patient consents, the regular GP may establish a patient's Core Journal that contains selected health information about the

3 ICT is shortened for information and communication technologies

consenting patient, which may be shared with other health care providers. The patient's Core Journal is extracted from the original journal and is physically stored on an external server. Authorized health personal may send requests to the server about a specific patient, and if certain conditions are approved the requested information will be automatically returned to the professional (without involvement from the regular GP). Information from other providers may also be included in the patient's Core Journal. The pharmacy could for example transfer information about prescription drugs a patient has received. The Norwegian Research Centre of Electronic Health Records has already investigated the possibility of integrating the PHR with the Core Journal in their ongoing research with *Eigen Journal* (Brasethvik & Kofod-Petersen, 2006).

A leading actor in Norway with regard to the tethered PHR model is the institution-specific PHR called My Record. The project managers behind My Record are Oslo University hospital and the Hospital in Telemark. The system has currently started a trial project where selected patient groups may access their discharge summary electronically by entering My Record. In addition, this system offers secure e-mail patient- provider communication; access to various health knowledge sources; several registration functionalities (concerning diet, medication, health expenditure and coagulants); discussion forums; electronic diary; and an additional functionality for appointment bookings with health providers. An interesting solution in My Record is the implemented BankID or BuyPass PKI authentication, which works via a shared login page or portal controlled by BBS. This implies that the My Record user has to confirm his or hers identity in the same manner as when logging on to his or her Internet banking.

TRSSID is an institution specific web portal for patients with a rare diagnosis, where the patients are enabled to perform secure communication with their healthcare providers at TRS national resource centre, which is a part of the Sunnaas hospital HE. Additionally the patients can access medical record via TRSSID that are written by the institutions healthcare providers.

Other systems that can be related to PHR technology is the web-based support system for cancer patients called *Web Choice* by the Centre for patient participation and nurse research, Oslo University hospital - Rikshospitalet. In this system the patient may report daily about the health situation (symptoms and problems). Furthermore, they can interact with professionals

and find relevant literature about cancer. In addition, the patients have option for writing an electronic diary.

The pharmacies are also included in trial projects of offering pharmacy services online. The system is called 'eResept' and is a system for electronic information exchange between the parties that handle prescription information, including the Norwegian Medical Association, pharmacy, bandages; Norwegian Medicine Agency; and the Labour and Welfare Organization (NAV). The doctors write an electronic prescription that is sent via 'The Norwegian Health Network' to a central database. From there it goes to the pharmacy or bandager, where the user collects the drugs from the pharmacy or bandager by displaying ID. An affirmative message returns to the central database after the user has collected the prescription drug or equipment, and the message is then sent along to the patient's EHR. The system is still on trial, but the intention with the 'eResept' is to improve communication between the different parties involved; to assure that the cheapest variant is prescribed; to check suitability and dosage of the prescribed drug; and to send documentation to NAV with regard to "blue prescription" (refunds). The users get access to their individual folder at 'eResept', allowing them to administer their medical consumption. The Norwegian Medicine Agency has developed a search base for medicines, which is going to replace the old medicine handbook.

The Health Authority in Denmark has less stringent laws than Norway with regard to health information exchange. The Danish health portal (http://www.sundhed.dk/) is a web based integrated PHR with access to a number of hospital's EHRs, and this system is highly advanced even in an international comparison. The portal provides patients with access to own hospital records, given patient consent. The system is event driven, e.g. information views are filtered by event trajectory showing diagnose; test results; requisitions; notes; observations; conducted procedures; and contact information with more. Patients are allowed to access the laboratory system and local EHR. The information is accessible for patients with a delay of 14 days. This is to assure that the doctor can bring critical health issues to the attention of the patient before it's accessible through the portal. The system has additional functionality including view medical record log, request appointments; request prescriptions renewals; and secure email consultation between patient – provider. Trough the portal, patients can also access clinical quality databases of patient-experiences, shared by prior in-patient in specific hospitals (with regard to the decision making the hospital). Patients are offered online self-service at the pharmacy, and drugs and equipments delivered to the door.

The portal also offers a wizard to interdisciplinary health providers, and patients may pick a regular physician based on selected criteria such as physician age and gender. The portal offers a package trajectory for patients that are diagnosed with cancer. These patients are provided with information regarding their illness-trajectory, and are guaranteed a maximum waiting time for treatment. Log on to this portal's was recently upgraded with online banking authorization called NemID.

2.1.2 EU perspectives

Most EU member states are developing a national e-health infrastructure that in the future will be interconnected (Clarke & Meiris, 2006) This infrastructure is based on NHS eHealth card (smart cards technology) called Electronic health cards (EHCs), or eHealth card. These cards store emergency; person identification; and permission to access medical services. In addition, the cards contain electronic prescriptions. They are going to be the key to the future planned PHR of the EU member states.

The National Health Authority in United Kingdom has developed a national healthcare portal, and provides healthcare consumers with practical information for navigating the healthcare system, as well as for accessing the Summary Care Record (SRC) online. Access to SRC is still on trial, and is currently not a service offered to all citizens. In addition, healthcare consumers are offered access to decision making tools, and to the option “No decision about me without me”. This is thought to make the consumers more engaged and committed in matters pertaining to their own healthcare. The system has features like secure online communication between patient and healthcare providers.

2.1.3 US perspectives

In the USA, the development of PHR systems is an emerging topic within the science of health informatics. The number of PHR vendors have escalated after President Obama pledged $19 billion for making every medical record computerized within 2014 (Obama, 2009). Not only does the US face challenges in getting doctors to upgrade from paper-based medical record systems to electronic medical record systems, they are also lacking adequate infrastructure to offer a cheap and stable internet connection to most inhabitants.

In the United States, the third party- and payer tethered PHR solutions are commonly used in the management of health information. However, even if several health portals are available today, patients are (with some exceptions) most likely to be entering health information themselves. Exceptions are PHRs offered by employers, incurrence companies or specific healthcare institutions (with a cost or indirectly cost).

Third party PHR systems like Google Health and Microsoft Health Vault are not regulated by the Health Insurance Portability and Accountability Act (HIPAA). The reason being that third party PHR systems are considered to be for users, and not for the healthcare institutions. If the users decide to store health information at e.g. Google Health, it is considered a patient right to access copies of own medical records. However, the third party systems often go into partnership with healthcare institutions that contribute patients to online access to medical record by use of e.g. Google Health. For such reasons, the regulations of HIPAA offer weak protection of patient privacy with regard to storage of sensitive health information.

2.2 Example of PHR systems

2.2.1 HealthSpace

HealthSpace is a national online personal health organizer. It enables the user to manage and store health information; to get overview of local providers; and to access “Summary Care Record” (SRC). HealthSpace is currently limited to persons living in early adopter areas within UK.

2.2.2 LifeSensor

LifeSensor is a personal health organizer that enables users to manage and store health information, and to assign access to others of interest. A useful functionality of this system is the LifeSensor emergency data chip, which makes it possible for healthcare providers to access the patient’s PHR by using his / hers emergency card. Additional functionalities are a healthcare appointment calendar; a health knowledge sources; and the ability to create an address book of current health providers.

2.2.3 Google Health

Google Health is a free web based PHR offered by Google that allows healthcare consumers to manage health information. Google Health has functionalities including health profile; import of medical records; prescription history; medical interaction check; request prescription renewal; overview of doctors and other health care services (which enable patients to get second opinions from doctors); and personalized health care information. Google Health has had great success in collaborating with strategic partners, like healthcare institutions that allow their patients to import and exchange health information electronically between the institutions and the Google Health user. In contrast, regular users of Google Health have to import or enter the medical record information on their own. One of the Google Health partners is Beth Israel Deaconess Medical Centre (BIDMC), with their PHR called PatientSite. PatientSite is an institution specific web portal for patients treated at BIDMC. When BIDMC are cooperating with Google Health, they are able to offer support to patients using content in medical records by permitting them to link PatientSite with Google Health. BIDMC is a teaching hospital of Harvard Medical School in Boston. The hospital is special in the sense that it has been using electronic health records since 1977. Other actors that have gone into partnerships with Google Health to enable an integrated PHR solution include Allscripts, AnnVita Health, the Cliveland Clinic, Blue Cross Blue Shield of Massachusetts, and Inland Northwest: 1HealthRecord, together with several others including a number of pharmacies.

2.2.4 Health Vault

Similar to *Google Health*, Microsoft has developed a system called *Health Vault*, which is an online health portal that offers functionalities including import; as well as storage and sharing of medical records from other data sources. The PHR has an option where emergency data may be viewed by the provider, either via web or via a phone to a call centre. Microsoft Health is working with strategic partners in the way Google Health does. E.g. the Canadian online health portal called TELUS Health space is integrated with Health Vault. Furthermore, *Health Trio, Aetna, Alliant Health* and *golem* along with numerous others are integrated with Health Vault in order to import and exchange health information.

2.2.5 Health Trio

Health Trio is a Dossia platform – (prior Indivo) that enables healthcare management to offer patients access to own medical records. In addition, patients are able to make their own contributions in dedicated areas within the medical records. This system includes current and past illness overviews; summary of surgeries and procedures; visit history; health calendar; patient report card; health plans; and immunization profile. The philosophy behind the system is that the patient retains control over his or her medical records. Thus, the patient chooses which data sources that will populate the record and who else are allowed to access and annotate the medical documentation (Mandl, Simons, Crawford & Abbett, 2007). The Dossia platform is an open source and it is based on the Guardian Angel manifest (Szolovits, Doyle & Long, 1994).

2.2.6 Health Record Bank

As a contrast to institution specific PHRs, *Health Record Bank* (HRB) makes it possible for healthcare consumers to take their medical records to the bank. HRB is a web-based tool that offers patients secure storage and medical records maintenance from multiple data sources. The solution offers patients full control over who is accessing their health accounts. The system is developed according to the principles by which financial banks manage their assets. Microsoft *Health Vault* and *Google Health* link patients to their HRB "bank account" where users may access, verify, and share copies of their own health information.

2.2.7 My Health eVet

My Health eVet is free governmental web based PHR for veterans, active duty soldiers, their dependents and caregivers. It provides management of healthcare information and services adjusted for veterans. The PHR was launched nationwide in 2003. The system provides veterans with access to healthy living centres; disease and conditions centres; mental health information; medical information; renewal of prescriptions by a veterans doctor; information about veterans benefits and services; local veteran events and activities; personal health records; vitals tracking and graphing; military health history, as well as exercise and diet journals.

2.2.8 Keas

Keas is an Internet based PHR system that offers expertise support to users, including explanations of health information entered into the user's profile. The system focuses on

health plans and on how to set health goals tailored to individual health histories. The *Keas* user is offered guidance on diet and exercise plans adjusted for age, gender and health condition.

2.2.9 Lifelines

Several PHR systems are developed to display medical record contents in more usable ways, including visualization of information. However, these more usable systems were primarily developed for healthcare workers, or for patient-access primarily in a clinical context in cooperation with well informed and technically savvy users. Plaisant´s Lifelines work within the area of information visualization is an example of such a system. Figure 5 displays a screen shot of the online tool Lifeline, which provide a visualization of the environment for personal histories. The figure presents an overview of an individual's medical patient records. Computerized personal health information is presented in a one-screen overview by use of timelines. Problems, diagnoses, test results or medications are represented as dots or horizontal lines. X-rays are displayed to the right in the screen. Instead of storing lots of files that may be suffering from unsystematic compilation of information, this way of present data provides an efficient and informative picture of a person's health information in a lifelong perceptive.

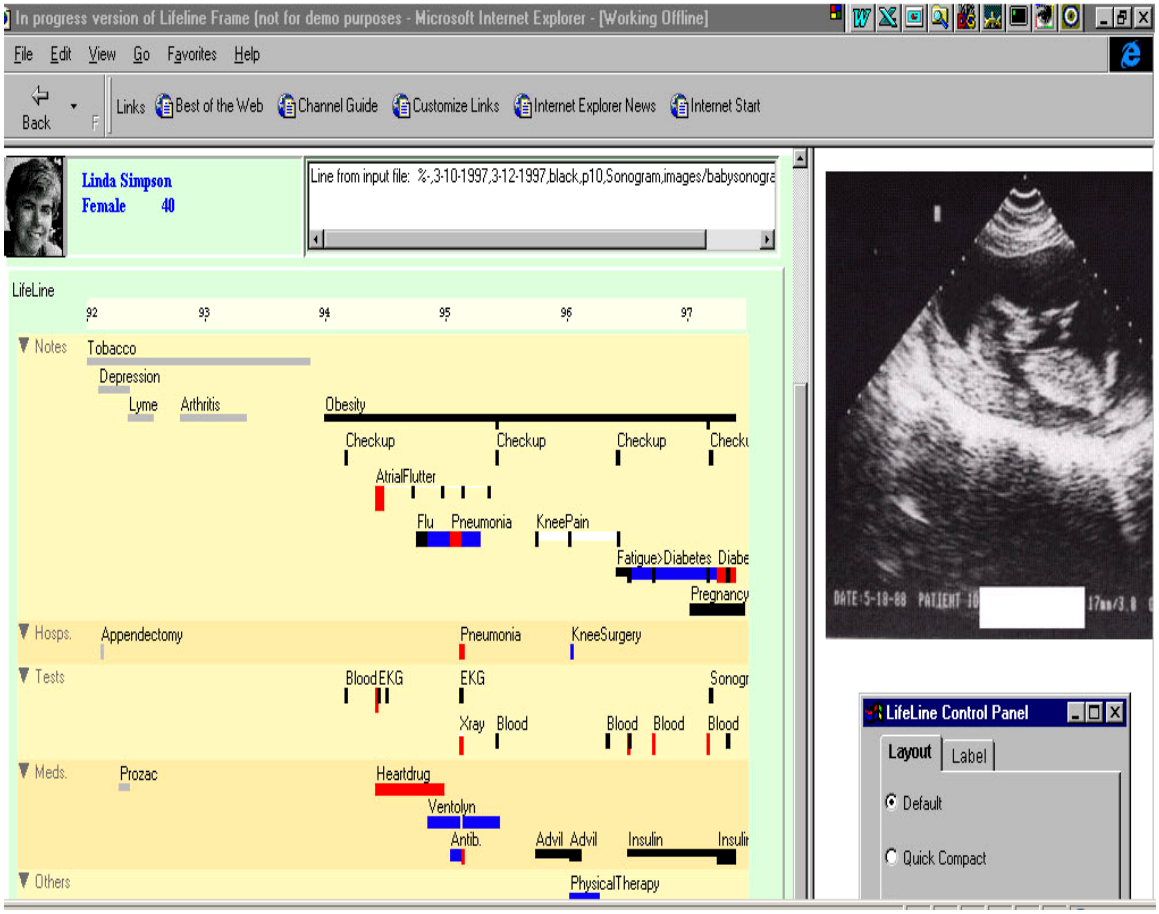


Figure 5: Print screen of Lifelines.

2.2.10 Lifeline 2

The second version of Lifeline allows the user to manipulate multiple records simultaneously, in order to understand relative temporal relationships across records. The aim is the discovery and exploration of patterns across records in order to support hypothesis generation, and find cause and effect association in a defined population.

2.2.11 PatientsLikeMe

PatientsLikeMe is a well-known portal for online disease-focused communities where individuals can organize their own experience base and utilize their own knowledge and insight, to achieve better health outcomes. Patients share information about treatments and symptoms, and use forums to exchange personal health information. The portal has a research team that collaborates with patients, academics and health industries. The research activities contribute to increased understanding of each disease served, and to the development of the

portal. The patient data entered is visualized by line graphs over time, placed over a background of population-level data. Furthermore, each individual's data is aggregated into community summaries of treatment and symptoms. The philosophy behind PatientsLikeMe is openness. The vendors build on a vision about transforming changes in health care system by "*speeding up the pace of research and fixing a broken health care system"* (www.Patientslikeme.com/about/openness). Participation is free of charge, and people all over the world are welcome to join a community.

The PHRs vendors are often targeting different phases or specific conditions in a person's life (senior, child, family, chronic ill, disease specific, traveller etcetera). Nevertheless, the aim of PHRs is that the system will cultivate a lifelong relationship with the user throughout these phases, going from one phase to another. The reason is perhaps to enable targeting of information needs to the users in an easy way.

2.3 Patients doing work

In this study, the patients' health information activities during the thoracic surgery trajectory, is recognized as "trajectory work" (Strauss, Fagerhaugh, Suczek, & Wiener, 1982). Strauss and co-authors were perceived as rather radical when they claimed – in the early eighties - that patients during hospitalization were doing work. Their view on patients' contributions is now widely acknowledged, and it is common to claim that patients should be supported with the necessary technology to better deal with their trajectory work. Strauss and co-authors describe a patient's trajectory as the physiological aspects of a patient's illness, which includes the overall organization of work required to serve a patient's illness path, as well as the implications this has for the actors involved in the work and organization. Strauss and co-authors refer to "trajectory work" as the management of a patient trajectory by the means of different types of work that is required to serve a patient's trajectory, and the inter-relationships between the various actors involved in this work (Strauss *et al*, 1982), e.g. research, monitoring, intervening and re-intervening in order to treat or alleviate the patients' health problems. Strauss acknowledge the patients work during hospitalization, but he refers to this work as often being invisible work, since health providers do not necessarily consider the patients contribution as work. Strauss also stress that chronically ill patients are often highly knowledgeable, since they are "experienced" patients, and often have been passively or actively involved in repeated test and procedures within which their surgery takes place. Strauss further pinpoints patient's scenarios during hospitalization in which patients make

contributions that should be recognized as work. These scenarios are listed below with examples.

- Expecting patients to work (e.g. share information about health conditions, drug use or reaction of drugs/treatment)
- Demanding patients to work (e.g. forcing reluctant patients to take medicine)
- Inviting patients to work (e.g. monitoring screens or take active part during a procedure)
- Negotiating patients to work (e.g. demanding patients to put their bodies in odd and painful positions during procedures like x-ray with a promise of an upcoming reward)
- Teaching patient to work (e.g. instructing patients about procedure, own care, drug use or monitoring)

Strauss and co-authors also discuss patient work during problematic trajectories and decision-making. During a surgery process there is likely to be both minor and major decision to be taken by the patients, and they often put in considerable effort in searching out information related to an upcoming surgery, the rehabilitation from it, and the prognosis. By introducing new technology that provide patients with access to relevant and accurate information, like own medical record and standard patient information, the patients would be better equipped to handle their work. The primarily focus in this thesis is on the part of the patient's trajectory that involves major surgical procedures, looking specifically at information needs during the thoracic surgery process.

2.3.1 CSCW

The patients activities are acknowledged as cooperative work, since patients and healthcare providers have to work together, and are mutually dependent on each other to produce the best outcome of a treatment. Basically, to give patients access to medical records, means that patients get access to information in retrospective time. This information will not support the patients during their surgery process, since the information available today is always a step behind compared to the patients need for accurate and timely information. Therefore, an information system supporting the patients during the surgery process has to contain more than mere access to records. My contribution in this thesis is to develop a health information system in which patients and healthcare providers can exchange relevant and necessary information. The idea is to give patients access to *prospective* information as well, and to

allow this information to be shared / applied to the system by healthcare providers. The prospective data would be standardized information related to the specific thoracic surgery process. Today, healthcare providers or their administrators send standard patient information about the surgery by snail mail to patients. This information may sometimes arrive too late if the patients are up for unscheduled / emergency surgery. In addition, the information may also focus only on the surgery and not on the thoracic surgery process / patient trajectory as a whole. The proposed information system includes extended standard patient information. In addition it contains stepwise information about what is commonly happening during the patient's trajectory. Patients could also give information to healthcare providers in return by filling out standard the patient information required by healthcare providers in advance of hospitalization, like for instance known allergies/cave, medication use and next of kin, etc.

The distributed work between the surgeons and their patients are highly interdependent in the production of healthcare services. For example, if the patient disobeys instructions before surgery (e.g. stop solid and liquid intake a fix amount of hours before surgery), the surgeon is not able to do her job. Likewise, if patients are not given the information required (like telling about intake of blood thinning drugs or previous history of anaesthesia allergies), or does not follow the post-surgery instructions, the work done by the surgeons is likely to be severely influenced. The information system in support of communication between patients and providers is acknowledged as a future channel for patients and healthcare professionals. Thus, I recognize the system in relation to the field of work called Computer Supported Co-operative Work (CSCW). The field of research called Computer Supported Co-operated Work (CSCW) is a research area still in the making, although it was initiated several decades ago. Currently several definitions of CSCW co-exist. I mention two. Jonathan Grudin (1988) defines it in the following way: *"How collaborative activities and their coordination can be supported by means of computer systems".* Schmidt and Bannon (1992) has an alternative definition: *"CSCW should be conceived of as an endeavour to understand the nature and requirements of cooperative work with the objective of designing computer - based technologies for cooperative work arrangements".*

Several CSCW scientists refer to their field of research as "group ware", a term commonly used by scientists focusing on designing software to support cooperative work. Moreover, CSCW scientists seem to have reached a consensus on being a design orientated research

area: ”Enter and you must change” (Carstensen & Schmidt, 2003). Note that this statement relates to the definition given above by Schmidt and Bannon.

Cooperative work needs to be understood in the context / environment it appears in, too better be capable to design useful group ware including the workplace within an organization or institution. In previous decades IS researchers were lacking theoretical approaches to analyse these issues. By looking at other disciplines the IS field has taken advantage of other theoretical framework from interdisciplinary fields of research. By doing so, the CSCW researchers have adapted social theories and applied them in system design of CSCW.

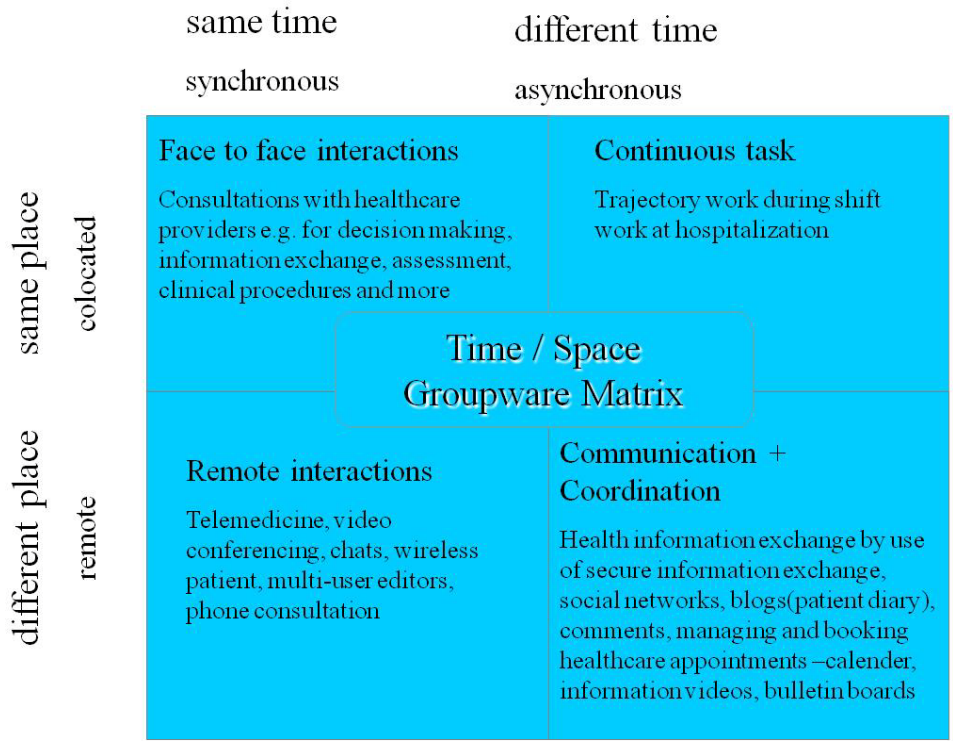


Figure 6: CSCW Time/Space matrix applied from Johnsen 1988, in Backer 1995, p.742

The CSCW matrix (figure 6) displays scenarios of cooperative work during the thoracic surgery trajectory, like where and when the patient and healthcare provider interact by use of potential group ware. After each face-to-face interaction or continuous task during hospitalization, relevant health information is updated in the patient’s medical record, so as to coordinate healthcare or / and future trajectory. The professionals note will be exchanged through the new technology, and stored for further reuse of the health information by the

patient. Groupware is an important tool for *awareness* so both patient and healthcare provider have shared knowledge about health information activities (Dourish & Bellotti, 1992).

When addressing cooperative work arrangements, it is referred to a mutual dependency between people, so accomplishing the work requires concerted efforts from these peoples. These arrangements may involve mutual dependency during production of goods or services. In the patient – healthcare provider arrangement, the mutual dependency is related to decision-making activities, as well as to the distributed work between the patient and healthcare provider during the thoracic surgery process. Both before and after the surgery itself, patients are instructed to given guidelines that are necessary for the outcome of the production.

The cooperative work arrangement between the patient and healthcare provider according to CHAT could be organized as a dialogue, or in several "perspectives" within the activity system (Engeström, 2001). In addition, the cooperative work could take place by mediation aided by a tool during the production of goods or services (Kutti, 1991)

Schmidt & Bannon (1992) argues that "the cooperative work is in principle distributed in the sense of decision making agents [that] are semi autonomous in their work." This also holds true with respect to the relationship between the patient and healthcare provider. A healthcare service may affect future illness trajectories for better or worse. As a consequence both patient and healthcare provider should strive for a mutual understanding of the consequences of a healthcare service provided, as well as a shared responsibility for the patient's health. Thus, both patient and healthcare provider could be considered semi autonomous decision makers. The patient's that receives healthcare also has to contribute with own work during production of the service. Of course, there are exceptions. For instance when the patient is in a condition were s/he is not able to speak up for himself/herself. In such cases, the patient is depending on relatives representing their interest of future illness trajectory – otherwise the healthcare providers have to consider the pros and cons with regard to the patient best interests.

An important concept in CSCW is the articulation of the cooperative work. The articulation work is integrated in the cooperative work, which according to Schmidt & Bannon (1992) is defined as "a set of activities required to manage the distributed nature of cooperative work". They further state that "*in order to articulate the distributed activities of cooperative work*

arrangement, access to appropriate means of communication is needed." The articulation work is not fully described within activity theory. The reason being that in a historical perspective activity theory was initially focusing on individuals, and not on communities. The articulation worker during a thoracic surgery process is likely to be an administrator – such as the patient coordinator or the department's head nurse- which together give instructions for pre- current and post hospitalization phases.

Carstensen and Schmidt (2003) together with others recognize that the CSCW community primarily has two dominant viewpoints in their field of research. The first viewpoint is a social approach that involves studies of how people perform cooperative work. The second viewpoint is a technical approach that includes studies of work practice needed to develop IT systems in support of cooperative work. This study involves both viewpoints, since both social and technical aspects are of potentially high relevance to the problem situation. Nonetheless, limited resources (in time and opportunity to observe patients during the thoracic surgery process) have resulted in a primary focus that attempts to understand the patients' part of the work as supported by useful technology. The applied theory in the project is activity theory. More precisely I utilize the adapted and extended version of activity theory presented by Yjro Engeström (2000, 2001). This method provides a constructive framework in the analysis of activities. Furthermore, the framework used in following design suggestions fits the recommendation by Schmidt & Bannon (1992) when it comes to choosing an approach that can be constructive rather than merely descriptive.

2.3.2 Activity theory

I have searched for constructive frameworks that of use in studying patients' health information activities. I found two theories particularly appropriate given the focus on patients' activities: *the theory of action* and *the activity theory*. Both of these theories have been taken into consideration. Anselm Strauss is the originator of theory of action, which is a framework for understanding work. He dedicated parts of his research effort to observational studies of work practice. His framework has in its turn been applied in several CSCW studies (Fitzpatrick, Tolone & Kaplan, 1995). Today his concepts are recognized in the research community; especially the concepts relating to action and interaction (action directed towards each other), together with the concepts of social worlds and sub worlds (Strauss, 1993). Strauss acknowledges the trajectory work. Following his view of patients doing work during hospitalization produces interesting viewpoints in relation to the topics in this thesis. Similar

to Strauss, the surgeons in Oslo university hospital Rikshospitalet acknowledge that patients need improved tools to support them during the thoracic surgery trajectory work. The question that needs to be addressed is: can Strauss' theory of action be used to a greater extent than merely in understanding to the trajectory work concept. E.g. could his theory also be informing the system design process? Initially the cultural historical activity theory (CHAT) stood out as a constructive framework for studying patients' health information activities, including system design. I shall use the third generation of CHAT, applied by Engeström (2000, 2001). The third generation builds on the previous generations, so the framework's development is not irrelevant (Nygård, 2010). According to Nygård (2010) the first generation of CHAT includes the goal orientated human that by mediation of a tool relate to the objective world. She further states that mediation shapes the human culture and history. The second generation of CHAT, developed by Leont'vn recognizes the collective activity, the meaning of the mediation and division of labour as a historical process (Nygård, 2010). Whereas Engeström (2000, 2001) apply the framework based on prior generations of CHAT, and introduces the activity system model. Engeström's third generation of CHAT has the activity system as the unit of analysis. Furthermore, Engeström acknowledges that the activity system is influenced by multiple viewpoints, conflicts of interests and norms that are shaped over time. The author stress that it is the contradictions and disturbances within the system that are the driving forces for change in the system. Strauss's theory of action is considered the closest related to activity theory in the research field of CSCW and human computer interaction (HCI) (Fitzpatrick, Tolone & Kaplan, 1995). For the problems of this thesis, I need a framework that allows one to include and distinguish social and technical components related to the unit of analysis. Both frameworks are deemed appropriate in this manner. However, the activities were motivated by a conscious purpose, and findings from prior studies have shown that activity theory is frequently applied and deemed appropriate for investigations of goal orientated activities mediated by artefact(s). Similarly the theory of action describes the activity as an interactional phase. Furthermore, Strauss theory of action has long tradition in the field of CSCW compared to the activity theory. In Strauss' theory of action, actions are performed in a setting of direct and indirect structural conditions that over time has the capability to change. The structural conditions and action / interaction reciprocally transform each other (Fitzpatrick, Tolone & Kaplan, 1995). This is a reminiscent of activity theory and its material context which is transformative. The strength of activity theory is the objective of change and the system of continuous evolvement. The activity system's subject and community share a common object, almost comparable to the theory of

action with its concepts like social worlds and sub worlds. An important concept in the theory of action is the articulation work, which is hardly mentioned in the activity theory. Strauss also acknowledges the interactional scope of work that includes individuals. The cause of the lacking support of articulation work in activity theory may be accounted for in the first generation of CHAT that includes the human individual and its mediation of a tool (Fitzpatrick, Tolone & Kaplan, 1995). The theory of action does not highlight the use of artefacts during the interactional phase. Thus, the activity theory seems more constructive when trying to understand activities in a system with components that mediate tools, rules and division of labour. In particular, I have found the activity theory to be useful in capturing the contextual and social aspects related to the medical record. A major challenge designing IT support to patients as they access the medical record is the shifting context of its use and re-use. From a cultural-historical view, the medical record has been firmly within the physician's domain as a working tool. The medical record is produced by and for physicians to coordinate healthcare services, and they are depending on and interacting with this tool in order to perform their work (e.g. assign a new in-patient, patient's updates, and check upon lab results or reading the nurses report about the patient, and so on). Today patients are likely to read their medical record, or at least the discharge summary, which is increasingly being handed out after hospitalization. Thus, it is limiting to study patient and health information discarding the original source that is primarily the healthcare providers. However, the physicians' might start to mediate the medical record differently when they expect patients to be a regular audience to their writing. By the same token, patients may start to act differently when they are guaranteed access to the medical record.

Activity theory is a theory that originated with the psychologists Vygotsky (1978), Rubinstein (1968) and Leont'ev (1978, 1981) in the former Soviet Union. The theory provides a framework that can be applied in studies aiming to describe the totality of work and human practice, and intentional processes meant to change these activities. According to Engeström (2001) five principles are considered central in the third generation of CHAT: 1) activity system as unit of analysis (in which an activity system is related to other activity systems), 2) multi-voicedness of activity (which capture the subject's multiple viewpoints, traditions and interests), 3) culture and historicity of the activity that evolves in shape, and change over time, 4) disturbance and contradictions as driving force of change in activity, 5) expansive cycles as a possible form of transformation in activity. Activity theory is a recognized framework in the field of computer supported cooperative work (CSCW), when studying work as goal-

orientated activities mediated by technology in organizations. Among the first to adapt this theory in user interface design was Susanne Bødker, in her project on newspaper production systems (Bødker, 1989). Kari Kuuti, shortly after, applied the framework in design, use and interaction in relation to computer technology (Kutti, 1991). Later Bødker, together with Bannon applied the theory to the analysis of human actions and interactions in mediation with tools in a cultural – historical perspective (Bannon & Bødker, 1990). Furthermore, Jakob Bardram applied the theory to study the dynamics of cooperative work activities in health care work (Bardram, 1998). Kaptelinin and Nardi (2006) contend that activity theory in HCI research provides a constructive and efficient framework for understanding structure, context and development of technology in support of activities. Last, but not least Engeström (2000, 2001) applied and extended the activity theory in his proposed work of the activity system model. Engeström's concept of an activity system is applied in this work when analyzing gathered case studies data, see Engeström's activity system model in figure 16.

It was Lev Vygotsky that originally proposed the single 'activity triangle' model that includes the subject and the object. Vygotsky was a revolutionary scientist, and his primary work on human development. In his work he conceptualized the tool and result methodology. In the epigraph to Vygotsky's "Thought and Language" (1962), one finds the famous Francis Bacon quote "neither hand nor mind alone suffice; the tools and devices they employ finally shape them". This perfectly catches the core in his framework. Yjro Engeström adapted Vygotskian's model, by including a third relation into the model- namely the community. By this Engeström supplemented the model with a social aspect capturing the social mediation of actions. This addition is illustrated by the second 'upside down' triangle in figure 16. Engeström thus recognizes cooperation within the system through dialogue and multiple perspectives in the activity system. Especially, Engeström recognizes the contradictions within and between parallel activity systems, in order to capture the collaboration process and generate development of potential change in the system(s). Kari Kutti identifies the collaboration within the activity system to be the mediating tool(s) that creates a product or service (Kutti, 1991).

In this thesis activity theory is used for the examination of the health information-related activities that surgical patients engage in, both prior to, during and after their surgical procedure. A problem with the studies referred is that the patient is not regarded as an interdependent actor in health care activities. This goes for Bardram (1998) as well as for

Engeström (2001). The patients' actions are described from the perspective of the healthcare professional. This study provides valuable insights by linking Engeström's healthcare provider's perspective to the patients'. Although, I do not use concepts like social worlds and action / interaction from Strauss, his concept of trajectory work is applied. The combination of concepts from these theories should be considered acceptable, since the theories are not in any fundamental disagreement, and the concepts used are not overlapping in subject. The concept of trajectory work concerns the time period in which the health information activities are performed, to place activities in both time and place. The thoracic surgery trajectory is drawn as a flow chart where the identified health information activities' are mapped within the trajectory. Use of the trajectory concept has been constructive both during interviews and in the system design process. (More details about the trajectory are provided methodology chapter). It turns out that the combination of concepts from activity theory and the theory of action is useful as it facilitates a comprehensive understanding of the problems addressed in the thesis.

3 METHODS

After approval by the Privacy Ombudsman at Oslo University hospital HE, Rikshospitalet's invitation of subjects to this study was announced to pre- and post thoracic surgery patients. Patients in these groups self-selected to the study, presumably based on their perceived need for health information during their upcoming or experienced thoracic surgery process. Participation required willingness to go through repeated interviews / evaluation meetings. Patients with residency in proximity to the Eastern part of Norway were preferred for practical and cost reasons (but this was not a fixed criterion).

3.1 Participants

To capture and understand user needs in the new information system, real patients were included in the design. They shared their patient experiences on a voluntary basis. Recruiting thoracic surgery patients for a participatory design study was no easy task. The two patients participating in the study were recruited by a forwarded invitation from the Chief surgeon at the Feiring Clinic located at Eidsvoll (a specialist hospital for heart patients owned by the National association of heart and lung diseases). In addition personal contact by a prior patient with heart illness was used in the recruitment process. Both patients finally recruited

for participation have received an aortic valve replacement at Oslo university hospital - Rikshospitalet. Apart from this their personal attributes varied significantly.

Given the limitation to merely two cases, the study is certainly not representative for the common thoracic surgery patient. However, the chosen approach (activity theory) justifies this restriction on the number of participants: Extracting actions from two participants alone generates a comprehensive a number of activities. This notwithstanding, additional participants could be recruited in future studies to extend and entrench our knowledge about the activities of thoracic surgery patients, and to adjust the standard patient information to accommodate larger user groups.

3.1.1 Participant A

Participant A is a female of age 42. She is born with a heart failure, and has been in frequent contact with the healthcare system since her heart failure became known. She is considered as an experienced and skilled patient in her interactions with healthcare providers. Her aortic valve replacement was carried out as a planned / scheduled thoracic surgery. A mechanical aortic valve replaced her defect aortic valve. The outcome of the surgery was unsuccessful. She is required to take blood diluting drugs for the remainder of her life, since her mechanical tissue valve induces an increased risk for blood clots. In addition, she carries an internal pacemaker after the aortic valve surgery. She lives in the countryside of Norway, and is dependent on a (fairly irregular) ferry boat connection to get to the mainland where the local hospital is located.

3.1.2 Participant B

Participant B is a male of age 70. He has experienced severe symptoms of sudden heart illness. Prior to this he was in good health. He is regarded as an inexperienced patient. As the symptoms emerged, his health condition was considered rather acute. He was put up for an emergency aortic valve replacement (an “unscheduled” surgery). He decided to get an aortic valve tissue of biological material, to avoid lifelong dependency of blood diluting drugs. He was considered a candidate for an internal pacemaker, but motivated his healthcare providers to wait and see – and by this avoided the pacemaker. He lives near the Norwegian capital and has relatively short distance to both local and regional hospitals.

3.2 Materials

3.2.1 Standard thoracic surgery trajectory

It was considered constructive to map the way thoracic surgery patients traverse the healthcare system, in trying to understand the workflow and the patients' health information activities. However, it turned out difficult to get a clear picture from administrative staff, as to the way the average patient is "processed" through the system. Prior research at the thoracic surgery department has resulted in an overview of standard patient trajectories from the GP via pre-examination (several assessments and evaluations), to the thoracic surgery department (TSD). The TDS imposes a common course through its different sections (TSD bedpost → TSD surgery → TSD Intensive → TSD bedpost) (Øyri, 2002). However, the overview is developed in order to understand which information is produced where in the specific subcategories of the EHR (Øyri, 2002). The present study – in contrast to this –provides an overview of the thoracic surgery trajectory with regard to the patients need for accurate and timely information in order to adapt at their future PHR technology. Lacking an overall bird's-eye view from the perspective of the patient, it deemed necessary to explore patients' activities further. Figure 7 displays the standard or general trajectory of the thoracic surgery process from entry (home), assessment (pre surgery), surgery, post surgery and end of surgery (follow up). However, patients do not necessary traverse the trajectory in a standardized manner. E.g. in problematic trajectory the patient might need multiple surgeries; or complications may appear so the patient is sent back and forward between the local and regional hospital; or the patient might be too ill to return to his/her home residence; and more. This notwithstanding, the flowchart is a useful reference of the patient trajectory, and a constructive tool when mapping patient activities in time. Additionally, the flowchart can be used as a support during interviews, to help patients memorize activities in time and phases within the trajectory. Thus, in practice the flowchart display the timeline for patient activities.

When studying the thoracic surgery patients' needs in relation to information access during each phase and time, one quickly realizes that the most of the medical record content is not timely accessible during the standard patient trajectory. Commonly doctors use voice recorders during initial documentation of the doctors' note. For this reason, weeks may go by before a medically trained secretary writes the recorded information into the patient's medical record. Thus, the content of the medical record is basically only accessible in retrospective time, and not during the trajectory. Therefore, one has to look elsewhere to support the

patients' information need and access during the trajectory. E.g. the gathered information from additional information sources could be standard patient information or adjusted patient information with regard to specific thoracic surgery procedure. In the future, use of digital speech recognition may induce the doctors to transfer recorded notes, and document processes, more quickly into the patient's medical record. At the same time, use of standardized patient information – that supports the patient in a timely way with relevant information during his or her trajectory – is recognized as essential in development of the new information system. Thus, production of standard patient information will require the involvement, interaction and commitment of resources from the patients' healthcare providers. Access to standard patient information is seen as useful since it provides the patients with a reference to what a regular procedure in a similar case during the trajectory would look like. E.g. in situations where the patients experience deviates from the standard patient trajectory, s/he will be better equipped to understand and compare own trajectory with the standard patient trajectory.

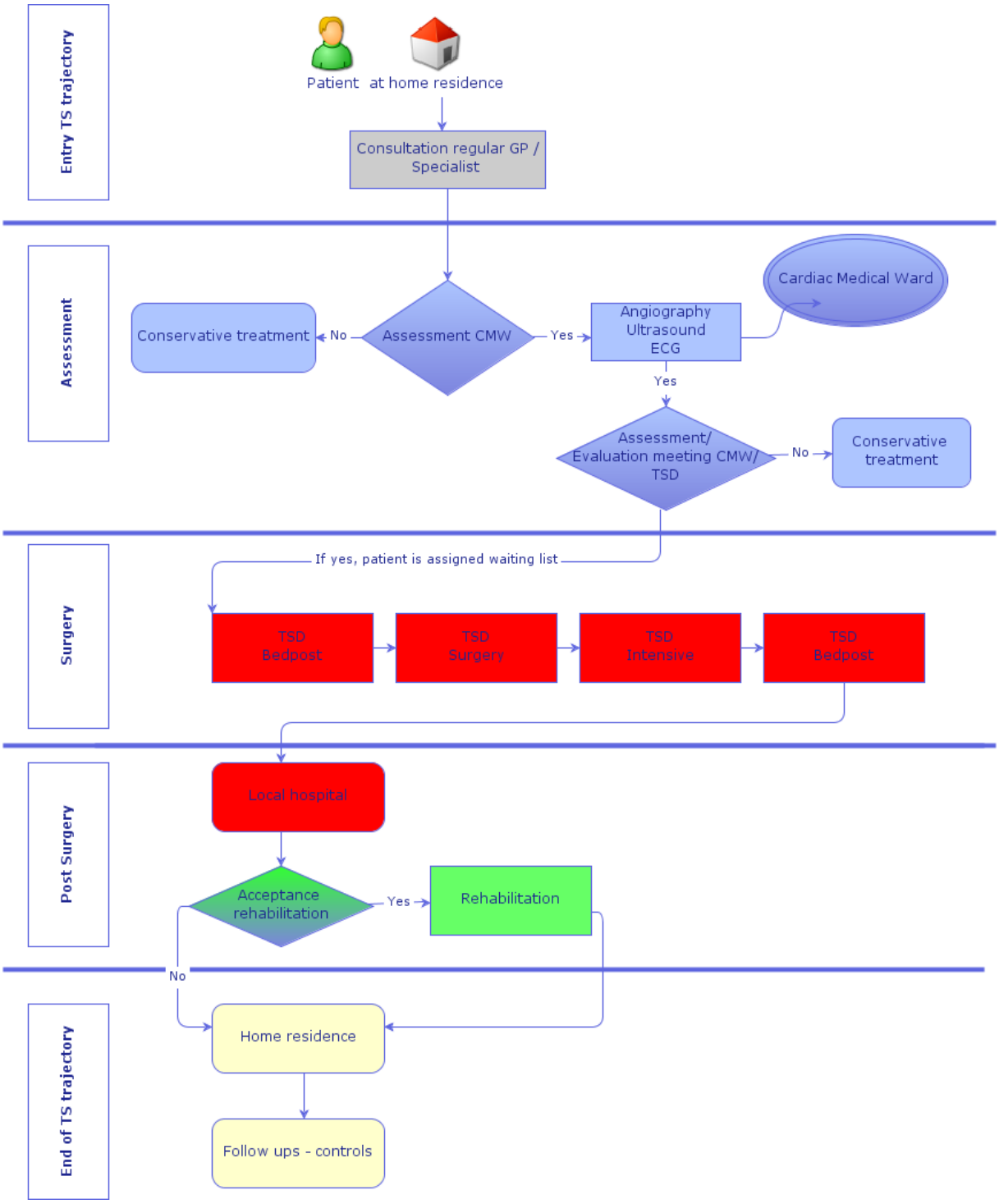


Figure 7: Flowchart of standard thoracic surgery trajectory

3.2.2 Initial health information mock-ups

Several initial paper- based designs of PHRs were sketched in advance and presented for the participants during the first interview. These designs included layout of the web based PHR system, and some commonly chosen PHR features with regard to existence PHR systems. The front page included a menu with selected common PHR features, which were presented with potential familiar layouts for the user. These layouts included Amazon.com; online banking; a web book; Web Forager search system with content as virtual books in shelves; fish eye detail interface design; and Tag cloud design. These six layout approaches were selected to represent a balance of textual representations (Amazon, online banking and Dossia platform) and visual representations (virtual book shelves, fish eye menu and tag cloud). As argued by Jonathan Grudin 1994 (in his listing of eight challenges for developers), one should use known interfaces with additional features to ease user adaptation. As noted this idea was supported in the design. All the layout variants used have the common characteristic that they refer directly or indirectly to the key word book, or managing content in a book. This is not a coincidence, since the system is thought to be associated with information navigation, or medical records that can be thought of as a book in a historical sense. Amazon is associated with one of the world's leading .com net shops, selling books among other products. Online banking offers administration of banking services online, while former bank accounts overviews were associated with the bankbook. The Dossia platform is an open source solution for PHR, which permits sharing of the medical record content between the healthcare provider and patient. A web book design approach is associated with a book that is navigated by turning pages with PHR content.

An information systems main objective is to present useful information to the user group. A central aspect of the design of this information system is to present information in a context that provides the reader with support when accessing this information. All EHR content is created in order to support healthcare providers, so the user of the PHR needs to be supported with extra features that make the EHR content readable for non-healthcare providers as well. Furthermore, the information system does not only need to be contextualized in a way that makes the content understandable. Design considerations should also include the needs of users with severe illness.

A selection of core features typically used in existing PHR systems were included such as:

- Contact information
- View of doctor's note (medical record content) with active thesaurus mark-up
- View of lab results with reference values

- Information visualization of medical record documentation presented in a single overview
- Toolbox for handling information in visual manner, such as an option for graphical presentations
- The option of searching additional health sources / knowledge base
- Inbox for secure communication with healthcare provider

These features were chosen because they are considered to be selected core activities in a typical future PHR system. Why did I not present the participants with a full paper- based PHR prototype? The reason for this is that the participant herself / himself should only be given a general idea about the support the system could provide them with during the patient trajectory. Hopefully this would release creativity in the participant, and make him/her come up with his/her independent suggestions for additional or alternative functionalities.

The illustration of the patient's contact information was visualized to make it appear as a personal information system. By adding this in the prototype presentation I was hoping that the participants would think about his/her own user account in a similar system.

The sketches included access to contents of the doctor's note (included in EHR), while at the same time highlighting medical terms and indicating the availability of dictionary functionalities (Thesaurus), as a teaser to the participants. Patients generally (and for various reasons) have an interest in medical documentation about themselves. However, a barrier for patients is an inability to understand the medical terms used in the files. The medical terms are used since the medical record in a cultural-historical perspective is primarily produced by and for healthcare providers. Researchers at IVS have developed and tested a Thesaurus integrated with EHR, for selected patients hospitalized in specific departments in Oslo University hospital – Rikshospitalet. Therefore the dictionary functionality was considered to be a useful tool to include in the paper-based prototypes.

The content of the medical record, not only give access to the original EHR document. E.g. a test result presented alone may not be appreciated as helpful by itself. Presenting the test result together with normal reference values might enlighten the reader. Thus, the screen view of a list of lab results together with normal reference values were added in the paper-based prototype.

Information visualization of the overall medical record documentation, presented in a single view is one of the main challenges in the system design. Therefore, it was natural to include several options for approaching the overview, and preferable early in the design process. As briefly mention above, the potential users of a future PHR for thoracic surgery process are suffering from severe illness. For this reason they might profit from information systems that focus on simplicity ease of navigation. At least they should be spared from a system with annoying animations that may increase their blood pressures or irritation levels. Thus, the information visualization should use subtle colours, a simple design, and avoid blinking animations or other annoying elements, such as overloads of mouse clicking behaviour, in order to get to the information content. The visualization of medical record content documentation overview is considered a core-functionality that was given high priority in the master thesis. The objective is to gather all health information content and present it in a single overview. The question that needs to be addressed in the first meeting with participants is how this overview should be designed to provide simple structure and common sense of navigation. To avoid a messy impression with overwhelming and chaotic labels, several solution of design / information visualization was discussed with the participants. In these discussions participants were encouraged to explore ways in which re-design of health information best could be structured to achieve satisfactory user experiences. The chosen approaches that were presented to the participants were as follows:

- Cover flow animation
- Web book and web forager interface
- Timeline view with fish eye view
- Folder structure similar EHR

Figure 8 displays the cover flow animation design, which is a further development of Web Forager / web book interface (Card, Robertsen & York, 1996). This approach has a fancy layout in which the user can navigate from beginning to end by displaying available content, document by document. The cover flow is commonly designed with a horizontal scroll bar for users to navigate through the content. When the user finds subjects of interest s/he can view the content in its full, and quickly access related subjects of interest. This approach is typically used for navigating through pictures, DVD rentals, CDs or other image items with limited text.

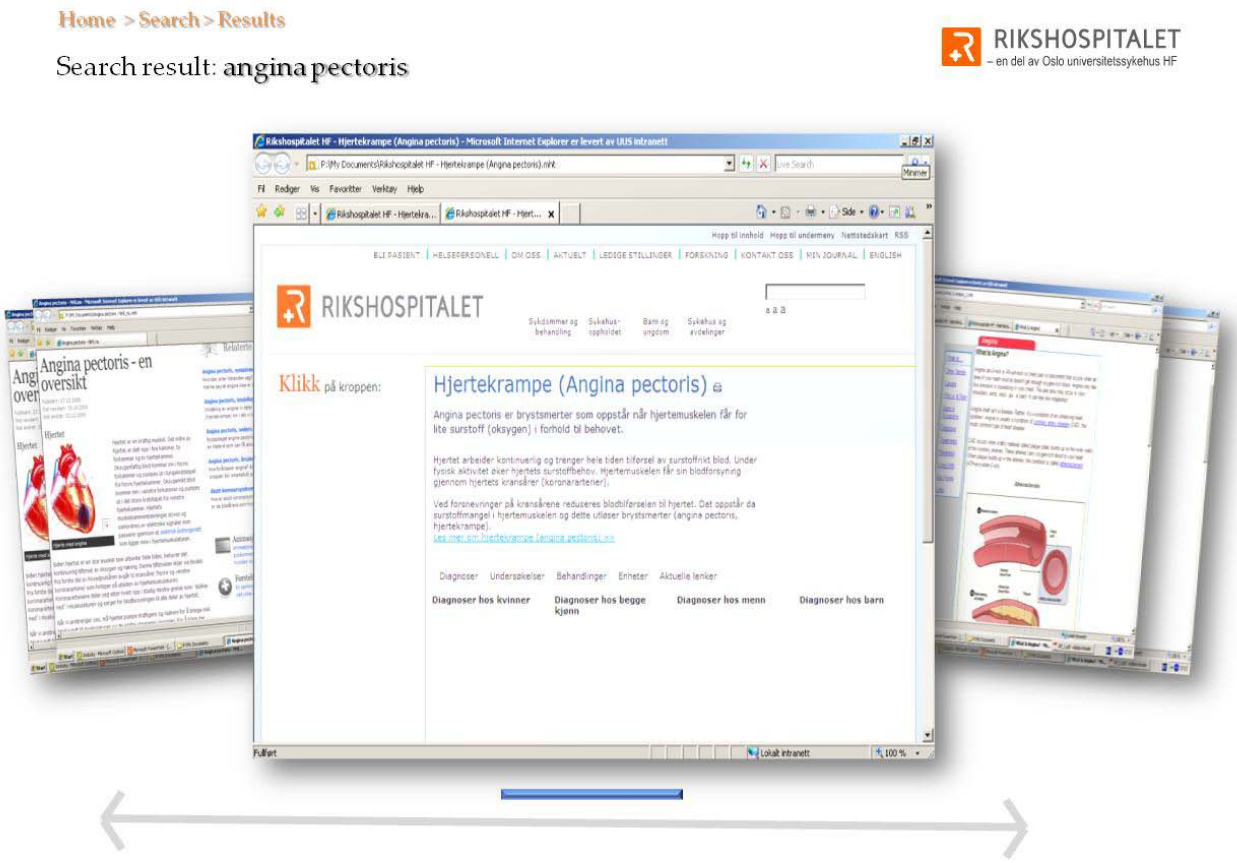


Figure 8: The figure displays how the paper based prototype of the cover flow approach may be used for visualisation information

The approach is also a popular and modern approach for display of search results. The drawback is that users with a heavy bunch of medical record content may perceive this navigation approach as cumbersome. However, this way of displaying information content may be better than only allowing manual navigation through paper copies of medical records, since an electronic system can find subject of interest more easily by query functionality. In particular, this approach should be taken into consideration when navigating repeated x-rays of subjects for the sake of comparison. Figure 9 displays how web book and web forager interfaces are used for visualization of the medical record content / search results. The web forager design includes virtual bookshelves that can be further explored with dimensional rendering (Card, Robertsen & York, 1996). This approach could appeal to the user since it makes visualization of books that could be associated with older medical record storage approaches. The drawback to this solution is similar to the drawback of the cover flow: users with a heavy bunch of medical record content that wish to go through the content covering an extended time period might perceive this way of navigation as burdensome. However, this

approach would fit nicely in design if the layout presenting all content as in reading a book appeals to the user (see appendix for drawn screen shoots of book layout design).

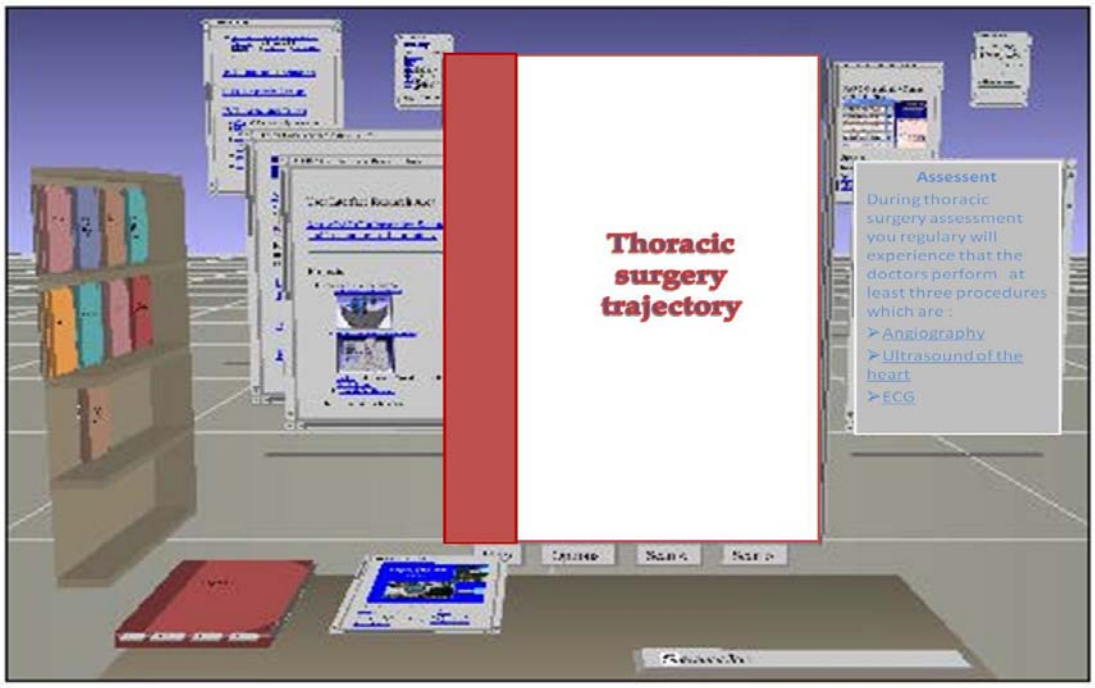


Figure 9: The figure displays the paper based prototype of how use of web forager design may be used to visualize information

The timeline with fish eye view (Hornbæk & Hertzum, 2007, Baudish, Lee & Hanna , 2004) interface provides a visualization of medical records linked to an event or other filters, and sorted by date and year (see drawn screen shoot displayed in figure 10). The interface displays an event label which requires clicking to access more information content, which could be linked to other record contents, that in its turn could be accessed by navigating further into the specific medical record using links within the content view. The timeline interface could be navigated by horizontal or/and vertical scroll bars. The fish eye view adds functionalities to the interface that highlights and enlarges the label title by event-driven mouse hovering. The timeline is advantageous since it structures events or other preferable filters (e.g. doctor; institution; procedure; or date intervals). To structure events by time might be useful when doing information search. In addition it offers a constructive method when organizing overload of information.

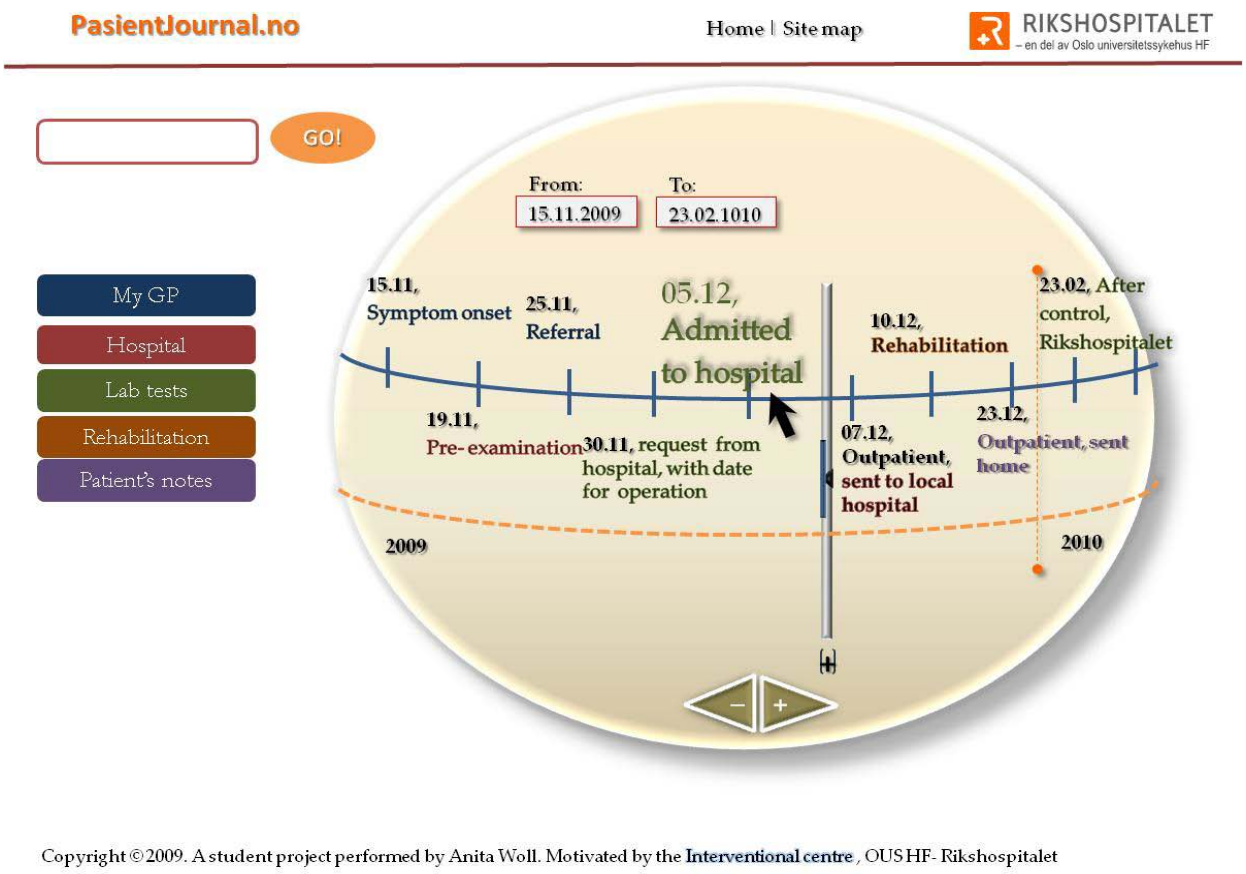


Figure 10: The figure displays the paper - based prototype drawing of timeline view together with fish eye menu.

Thus, the timeline interface makes for easy navigation through the content, and allows the user to search after subject of interest. A complex timeline with too many filters, scrolling options or clicking behaviour to dig further into the information might be considered burdensome to the user.

Figure 11 displays how advanced map folder structures, similar to the EHR technology, could be used for information visualization that includes timelines. This view offers users simple and intuitive access to medical record contents of certain dates and professionals. Patients as users are likely to feel comfortable with the folder as icon, which is familiar from the paper based medical record. The flip side is that this design approach is less flexible with regard to finding special events, though this can be solved by an advanced search function. Since this design approach resembles the old fashioned paper based records, it would be time consuming to go through every record to find subject of interest if the patient has a long history of healthcare services. In addition, the information content is hardly organized in a patient friendly manner as it is separated into professionals as mention above.

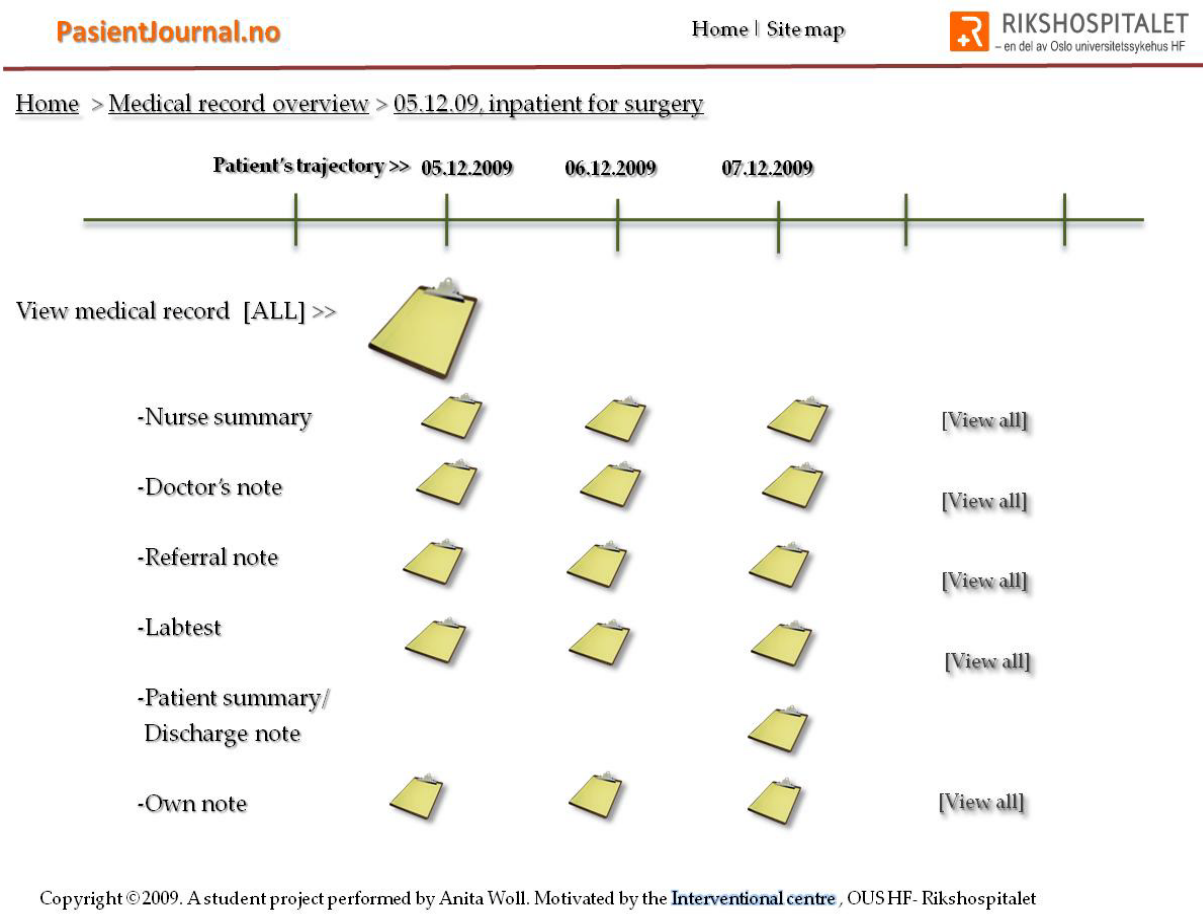


Figure 11: This figure display paper based prototype drawing where information is visualised similar EHR folder system

As a supplement to limited dictionary functionality, the information system needs options for searching additional health sources (e.g. integrated knowledge / information database). There are several health knowledge sources that could be added to the system, so this functionality needs to be discussed with the users early in the design process. Various solutions to the re-use of search queries and search functionality might be implemented into PHR:

- Sandbox
- Keyword typed into an entry field
- Search assistant
- Overview display with query term marked with highlighting with additional overview on a web page
- Knowledge base including thesaurus and other relevant knowledge sources like Up-to-date, BMJ Best Practice, Norsk elektronisk legehåndbok (NEL), Felleskatalogen, clinical Evidence, FinnKode (ICD-10), Norsk legemiddelhåndbok and Oncolex.

The Sandbox (Wright, Schroh, Proulux, Skaburskis & Cort, 2006) is a toolbox where drag and drop from e.g. timeline labels can be further re-used (see figure 12 below for illustration of paper-based prototype of such scenarios). A toolbox for editing and re-using information in a visual manner (e.g. an option for graphical presentations of a specific lab result taken over time) is included as an advanced feature. This feature, however, will not have a prioritized focus in this thesis, but is merely included to show the user that the system could be expanded in a more practical direction for advanced users. In the future, I guess that the PHR system will be developed to include several other tools than those needed to read and get support in reading the information content. Potential features are likely to include more interactions with the information and interactions involving advanced re-use of the information content. Such features can then be used in decision making process, or to investigate the course of health issues (e.g. deterioration or improvement in specific indicators like blood tests).

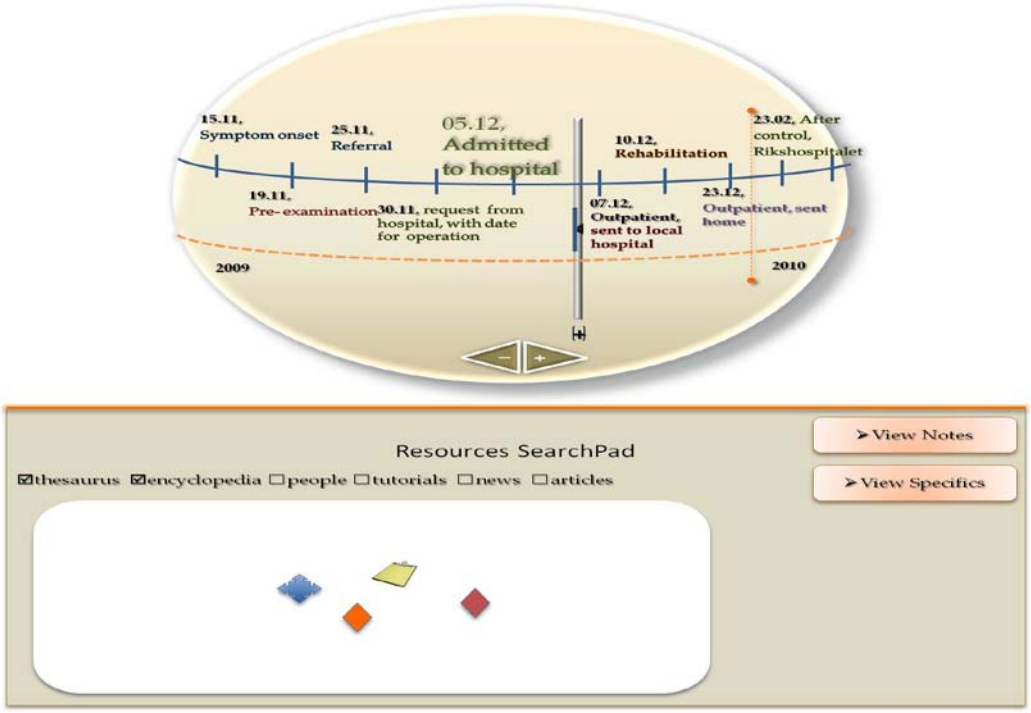


Figure 12: Paper - based prototype displaying sandbox as resource tool area for timeline view with its events.

The approach punching a subject of interest (keyword) into an entry field (“aortic valve material”) is probably the most common search interface. This functionality is also familiar to users that seldom approach web based interfaces. This search interface might be considered

boring to the advance user, and finding effective key word for queries could be perceived as a difficult task. Furthermore, a drawback to this interface is that it lacks re-use opportunities of previous queries, and therefore requires the user to write down repeated search key words. The 'search assistant' (Hearst, 2009) has become more frequent, and it can assist users in completing initiated entries of keywords, in correcting spelling errors ,and in handling prior searches for re-use. The search interface that displays an overview with query terms marked by highlighting, and additionally also display the full web page of the specific search result chosen (Baudish et al, 2004), is an effective approach for quickly finding relevant information in a search. The only drawback is that the webpage displayed together with search results might appear in a reduced display, which might impair ease of reading. Since the medical record content is produced mainly retrospectively, the user needs additional sources of information to get the knowledge needed during his/hers patient's trajectory. Links to a relevant 'Knowledge base' should therefore be made available in the PHR system in order to support user with supplementary information. Relevant knowledge sources could be Up-to-date, BMJ Best Practice, Norsk elektronisk legehåndbok (NEL), Felleskatalogen, Clinical Evidence, FinnKode (ICD-10), Norsk legemiddelhåndbok and Oncolex.

These sources could both be relevant when searching out information for decision making, in mental preparation prior to procedure, or as a support when reading own record content after the procedure is finalized. Additionally, the dictionary functionality (Thesaurus) mentioned above should support the user when reading and dealing with terms that need further description. The PHR system should function as a communication channel between the users and their healthcare providers. A must-have feature in this setting is a mailbox, with in-box for secure information exchange between the patients and healthcare providers. Especially, in unscheduled surgery situations, an electronic mailbox can contribute essentially to the speeding up of information exchange. Today, healthcare providers may not reach the patients with pre surgery information before s/he is hospitalized. Thus, the mailbox should be considered one of several necessary features to include in the system requirements.

3.2.3 Review of the medical record

It is necessary to review the historical development of the activities and the mediating tool according to concepts in CHAT, to raise the awareness of the role of its culture (Vygotsky, 1978). Vygotsky claims that the mediating tool develops historically, within groups, and also trough individual interaction. This shared knowledge of cultural mediation is a process that

Vygotsky refers to as internalization. He recognizes the internalization as “knowing how”. The shared knowledge of cultural mediation could also be applied to the medical record. The medical record has in previously decades been a tool primarily for healthcare providers. However, as the patients are accessing and using the medical record more regularly, they need support in using the record content in order to benefit from it. Furthermore, Vygotsky’s internalization relates to the appropriation of the tool, in which the patients have to make the tool to their own tool. For this reason one must be open to the possibility of patients using the medical record in a manner not originally foreseen. The internalization of the medical record refers to the way patients use the tool for their own need, rather than using it in the same manner healthcare providers do.

The medical record is a central working tool for healthcare providers, whose main task is to provide healthcare to their patients. In Norway the existence of medical records written by doctors goes back to the eighteen century (The city archive of Bergen, 2010). The medical documentation in its early development was written by and owned by the doctor. This documentation was therefore called the doctor’s record. In the 1920’s doctors wrote notes about patients containing health information formulated with expression based on both discretion and facts (NOU, 2006:5). This reporting of patient information changed in 1940, when written reports started to include formulations based only on facts, while excluding all references to discretion and interpretation of the patient health situation (NOU, 2006:5). The reports were written in dedicated books during the course of treatment. In the 1970’s there a new shift in the patient report organization came about with the introduction of the Kardex system (NOU, 2006:5). The Kardex system initiated continuity in care, with overview reports for each individual patient. In addition, the patient’s care plan was introduced and integrated in the medical record system.

In 1977, a Norwegian dentist established his statutory right to access own medical records after consultation and healthcare treatment (NOU, 2006:5). Following treatment at a public hospital, he demanded access to own medical record. He was given the right to do so, without legal statement from the court that had required the hospital’s medical record as evidence in the first place. The access given was constrained by the requirement of equal limitations, as laid down in the law of Public Administration, § 19. This ruling was based on general principles and legal interpretation, since the question was not considered fully regulated by the law of Public Administration, or the law of freedom of information (Supreme Court 1977-

10-25). Based on the statements by the Supreme Court in the seventies, all patients (barring some well defined exceptions) got legal rights to access own medical records in 1980. This was a major breakthrough for the patients' rights, and the medical record was from this moment considered more "public", since not only professionals were granted access. As a consequence, today the medical record is viewed more as a patient record than a doctor record.

In 1994 the medical record was re-organized in categorizes for interdisciplinary professionals working in healthcare, including doctors, nurses, physiotherapists, bioengineers with more (NOU, 2006:5). Several healthcare institutions upgraded from paper- based medical record systems to electronic medical record systems. Thus, as the health care services developed over time, the scope of the health documentation changed. Advanced and high technological medical equipments have contributed to the drive towards more comprehensive medical records in the years following. Today the medical record is recognized as a legal document, which requires every aspect regarding the patient's health to be documented.

In the late nineties, several health institutions upgraded from paper-based record system to electronic health record systems (NOU, 2006:5). The EHR makes the electronic record available for authorized healthcare providers regardless of time and prior location of use. This stands in stark contrast to the practise in the early days, when paper-based records had to be physically moved from place to place. Today almost every healthcare provider in Norway uses EHR. Older paper-based records are often scanned to be accessible in electronic format, since during a patient's hospitalization the medical record is required to be accessible for each provider delivering care. Given current health legislation, every healthcare provider group is obligatory to independent documentation (NOU, 2006:5) therefore as well the record needs to be accessible. The specialist healthcare services like hospital services have routines for documentation of patients from arrival to discharge. Their recorded notes are primarily meant as a working tool for healthcare providers within the hospital. The notes are written mainly retrospectively for awareness and coordination in healthcare within the institution and between institutions. The record is not structured, meaning that the different providers may write freely about issues of concern. However, topics included in the record are to some extent predictable, like information about diagnosis, present status, interventions, allergies and medications, with more. Healthcare providers on duty interact with specific patient medical records during a day of hospitalization. Information in the record is produced and re-

used by several health care providers to achieve continuous care. However, the medical record is also serving other purposes, such as referral and patient summary; internal assessment and quality insurance; documentation in litigation or patients complains; research; basis for forensic and dental examinations; education and training of healthcare providers; administration; supervision of county physicians and state Board of Health; and for patient to get knowledge of own health (NOU, 2006:5).

3.3 Procedure

The system requirement was allowed to evolve by use of iterative development process in collaboration with the participants. The reason being is that the study is a participatory design study, which depends on interface prototyping and user participation throughout the interface design stage (Norman & Draper, 1986). Thus, the set system requirement is developed and adjusted during the study. This method is chosen because the project's main subject is to understand the patient's activities, and to use their knowledge in design to best support them with new technology. The patients are the key user of the system, but the healthcare providers are also important actors in relation to the new technology since they provide the patients with documented and / or oral information. In addition, the thoracic surgeons and nurses have first hand knowledge of the patient – provider relationship; hence contribution from them will make the system more inclusive. The selected design approach may be emphasized further. Other system design approaches like the waterfall method was rejected, since such an approach is more beneficial for development where requirements and procedures are precisely described at an initial stage. This project cannot pursue a sequential flow without loss of user friendliness. The project will therefore use an iterative development with user-cantered system design, since it seems natural to develop, test and refine the user interface via regular feedback with the informants.

The listed procedure (see figure 13 below) displays the stepwise iterative approach that starts with the first interviews and ends with the second interview. As the final step, evaluation is carried out. It will be necessary to re-loop the procedure list from step one to four. The reason for this is that new or additional information will be gathered during the final interview by the participants. Thus, the analysis needs to be adjusted after taking into account the new information. Likewise, the system requirements have to be adjusted according to updated analysis. Thus, adjusted system requirement requires re-design considerations. Based on the

final design considerations, I will suggest a web based prototype of a PHR for thoracic surgery patients. Evolutionary prototyping is used during the process. An initial interface will be produced and evaluated by the patients and adjusted until the patients are satisfied with the system. The prototype evaluation will focus on the information visualization, user expectation and how the patient activities are supported by the new technology.

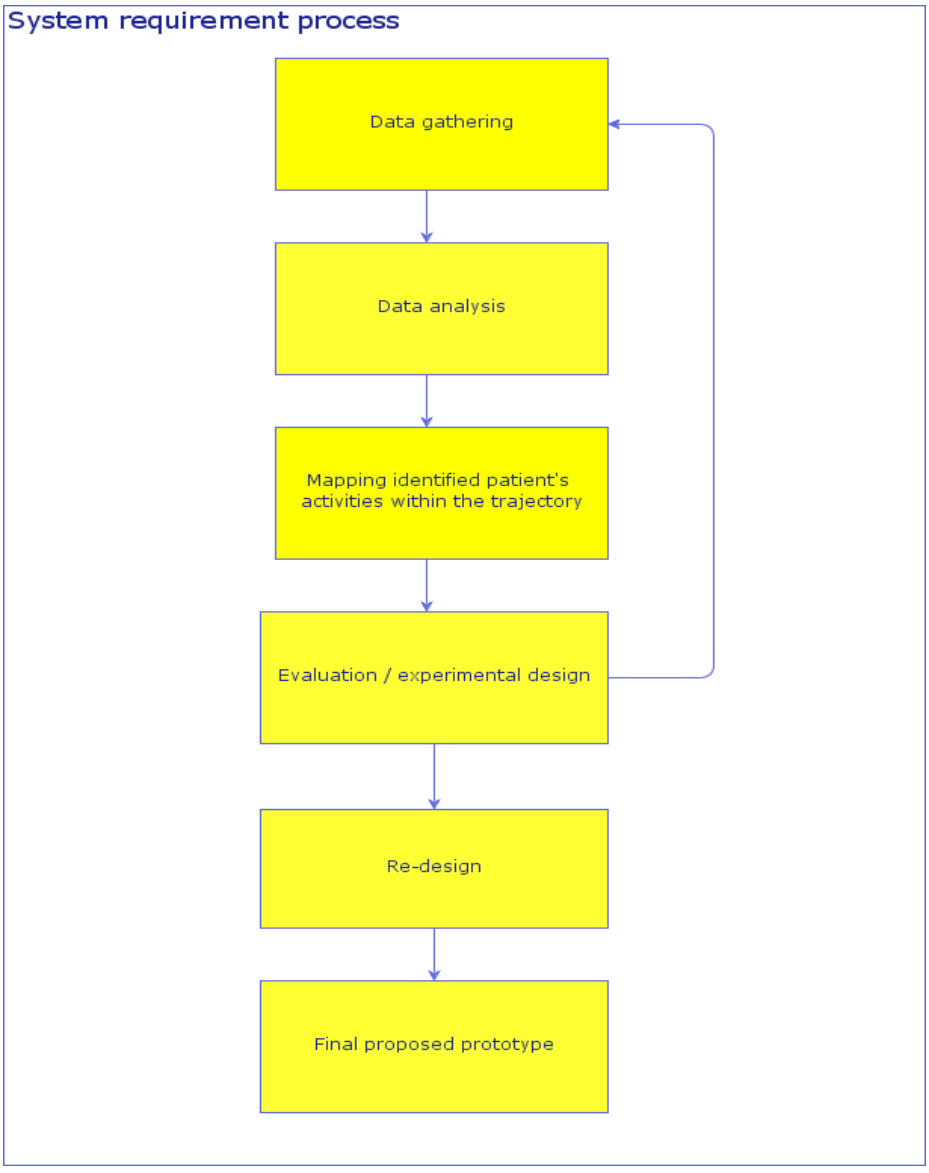


Figure 13: Overview of the system development specification process

Not until the patients are satisfied with how their activities are understood and supported by the prototype, a final prototype is presented in the project. Before the meeting and initial

interview with the participants, several design suggestions need to be presented to the participators to make them understand how the new technology can be useful to them, and can empower them as patients. The reason being that no assumptions are made about the participants' knowledge regarding the potential system design and development. The initial drawings are used as ideas to release the creativity of participants with respect to the future design of the system.

3.3.1 Interview procedure #1

Story iteration 1

The first interview with the participants was carried out by questions included in the case study, and the patients were invited to freely express their patient experiences. The questions included were about age, gender, technology skills, services that patients use at Internet (like reporting tax returns, online banking and change of GP), current management of personal health information, sources for health knowledge, familiarity with health literacy, potential usefulness of various functionalities in a PHR, and the patient's information need and their experience with information flow between themselves and professionals at the hospital (see figure 8). Secondly, the participants were shown prototype drawings of a number of GUIs of PHR systems, and were asked questions for evaluation of these prototypes (see figure 9). These questions included the visual impressions and functionalities included or missing in the screen shots. They were also asked which information they were especially interested in with regard to their provider's EHR documentation, and how this information could be displayed most conveniently in a transparent manner in the PHR. Furthermore, they were asked how all their record content could be organised as a whole; how they wished to explore the content in the medical records; how the PHR could be used for searching additional knowledge sources; and again how this additional information could be displayed to the patients in a way that make sense. In the end the participants were asked to grade a number of functionalities that are frequently included in PHR system, from grade 1 ="not important at all" to 10 ="Very important". The main objective was to explore how the patients would like the PHR designed, inducing them to administrate their health records based on individual needs and patient work. The participants were asked to focus only on the time period that was tailored to the thoracic surgery process, and likewise with respect to functionalities related to this trajectory work. The initial interviews had an average duration of 2 hours.

INTERVIEW PART I
Q1: Contact information
Q2: Birth date
Q3: Gender
Q4-5: Are you handling your bank accounts, change of GP and taxes online?
Q6: Would you care for having access to all your health records via Internet?
Q7: How often are you using Internet? (Options: daily, weekly, monthly, seldom, never)
Q 8: What personal health information are you keeping for later use?
Q9: How do you organize this information (related to question 8), like do you have a system for storage?
Q10: Have you read your own patient records?
Q11: If yes (question 10), what was your motivation / motive for reading your patient record?
Q12: Would it be OK for you to get a copy of your record automatically after being
Discharged from your provider?
Q13: What kind of information are you getting before an admission to the hospital?
Q14: Is it information or procedures that you would like to get more thoroughly described?
Q15: Have you experience that you has to contribute yourself with important information to the health providers?
Q16: Do you check that your health provider has updated information about you?
Q17: What type of information are the surgeons transferring to you?
Q18: What type of information are the nurses transferring to you?
Q19: What type of information are the nurse assistants transferring to you?
Q20: Do you get the impression that you have an influence and shared responsibility
mutually with the doctors when it is taken important consideration regarding your health
Condition?
Q21: Additional comments about information need

Figure 14: Overview of case study questions part I

INTERVIEW PART II
Q1: What ideas and possibilities do you see in a PHR system like this?
Q2: What kind of functionalities would you say are most important?
Q3: What is missing in this picture, are there other support functionalities you are missing?
Q4: How should a PHR is designed for you to use it?
Q5: Is it useful for you to get access to your records?
Q6: Would you like to write additionally comments into the records?
Q7: Grade the functionalities based on the usefulness it has for you. 1 = not at all important, 10 = very much importantMedical history
Patient summary / discharge note
Lab tests
Record log (who have accessed my record)
Medication overview
Allergies / cave
Update contact information of relatives
Share information with relatives
Make new appointment online
Vaccine overview
Vital measures
Own notes
Rehabilitation plan
Alert / risk profile
Access to medical knowledge source
Renewal prescription
Alert before doctor appointment
Communicate with providers
Communicate with other patients
Online health shops
Participate in research projects

Figure 15: Overview of case study questions part II

3.3.2 Interview procedure #2

Story iteration 2

Interview #2 gets participants to evaluate the standard- and individual thoracic surgery trajectories. The standard patient trajectory was presented to each participant, in addition to the individual thoracic surgery trajectory displaying flow chart of mapped activities. Thus, each participant was able to adjust my translation and present viewpoints of their activities with regard to their translation and recalled memory. In this process the participants were presented with a screen print in A3 format that included a timeline containing the different phases within the standard patient trajectory, like GP consultation; assessment; evaluation meeting; surgery; post surgery; and follow up controls. The participants were then invited to add notes on the preferred labelling of content linked to specific timeline events. Participants were allowed to decide which information they found useful and how – in their view – the EHR documentation could be supplemented with standard patient information. When the participants had finished adding suggestions of content, the timeline was photographed for memorization and compared to the other participant's design contribution. In addition the participants were asked to evaluate the quality of the identified and mapped activities using Engeström's activity system model concepts within the main phases of the trajectory.

In the end of the final interview, participants were invited to do experimental design by putting notes of objects into prototypes of timeline views. To facilitate this I brought an A3 print out of the timeline, together with labelled notes about objects within the patient record, such as lab tests, medication, and other monitoring tests like blood pressure; heart rhythm; SPO2; with more. These objects were associated with essential health information considered useful to heart patients such as medication (e.g. blood diluted medication); heart rhythm; blood pressure; oxygen saturation; weight; and lab results with more. Monitoring of heart rhythm, blood pressure and oxygen saturation were said to be thought of as self monitoring with related home equipments (e.g. sensors that in the future would allow wireless monitoring of patients from their homes). These measurements could then later be transferred to healthcare providers for evaluation, or just used as essential information during follow-ups. Home monitoring of patients may be more accurate with regard to daily life activities, and reducing or avoiding so-called office measurement bias (E.g. it is well known that blood pressure may be affected when taken in the doctor office, as it is influenced by the context and the doctor presence). Subsequently we discussed the main concerns of the participants, at this point of care. Through conversation and paper based design, the participants developed

their own timelines of object(s) that they found necessary to visualize to support their future trajectory. The design process was considered as constructive, whereas the patients' were able to quality check my understanding of their activities and information need. In addition their current needs were taken into account. The follow up interviews lasted on average approximately two and a half hours. The added design suggestions were photographed for further memorization and re-design.

3.4 Analysis

3.4.1 Interview #1 analysis: Activities

The gathered empirical data from the interviews were de-identified by replacing personal identification with a code, by use of code list. The information was analysed and structured after patients' activities by use of Engeström's model of an activity system with regard to subject; tool; object; laws; community; and division of labour. The interviews were read in such a way as to find all the actions taken by patients and the healthcare professionals' actions described by the patients. Using this framework, specific events from the patients themselves was organized in a system of meaning related to context, work and information need. The 24 activities were sorted in a table overview (since drawing all the models would be too overwhelming, see figure 17 below). Only activities revealing major information gaps were drawn for further investigation of disturbances in the system. Based on the outcome of each action I was able to suggest design considerations.

In addition to Engeström's components, I have identified three complementary resources to support the system design process. These resources are motivation; information source; and design consideration. It is an assumption that use of CHAT involves intentional activities. However, this intentionality is latent within the system and it is up to the reader (and his world view) to freely interpret the motive behind the individual action. In this study, when dealing with a number of activities, it was useful to identify the motivation behind the activity. Recognizing the participants' motivation also made it easier to understand the meaning of the patient's work more explicitly. Similarly, identification of the information source was helpful when analysing the "if and how" questions of how a possible transfer of information could be done, to better support patients by new technology. Based on the activity system, motivation and information source it was helpful to make design considerations to the new technology.

The design suggestions are considered as initial design consideration of the proposed PHR. Design suggestions included in the prototype is presented in the chapter called system requirement, and the suggestions are subsequently further refined by use of participatory design and evaluation. Several design suggestions require extra work obligations of the thoracic surgery department staff, thus the suggestions have to be presented and discussed with them to achieve the potential of the new technology.

3.4.2 Cultural historical activity theory (CHAT)

According to Engeström the activity system model provides the simplest form of a unit of analysis that includes three mutual relationships between subject, object and community (Kutti, 1991). Engeström (2000) further claims that each of the mediating terms are culturally and historically shaped, and continue to evolve over time. Kutti emphasizes the character of the development by " the development is not smooth and linear in character, but rather uneven and incoherent, and driven by various contradictions" (Kutti 1991, p257). As Kutti explains by the statement "the corresponding mediation of members is continually being reconstructed during the existence of an activity" (Kutti, 1991, p257). In his research, Engeström (2000, 2001) applies this framework to the study of change processes in organizations, primarily health care organization. Engeström acknowledges contradictions as the driving forces in the change process that could "offer possibilities for expansive developmental transformations" (Engeström, 2001, p 960). The ways activities are performed in health care systems are grounded in tradition. The patient record is primarily used within the health institution, and to a lesser extent outside these institutions, however this is a developing process that may change over time. The problem situation in this activity system is identified as a design project of a new technology that supports patients during their thorax surgery process. This new technology could possible transform health care service for patients from being health care receivers to becoming upgraded as empowered and active participants during health care management - autonomous individuals that are included in decision making concerning own health and future trajectory work. The activity system model is further explained in the analysis.

Engeström's activity system model is shown below (in figure 16), using an example from his paper on redesigning work in healthcare (Engeström, 2000, p 965). In his work, he established

a simple structural model of the concept of activity consisting of *subjects*, *objects*, *tools, rules, community, division of labour,* and *outcome*. The relationships indicated in the figure are a working hypothesis for Engeström (2000). He recognizes contradictions (emphasized by the lightning shaped arrows) in the healthcare system as the driving force in the activity system, displayed as the *outcome* of "gaps, overlaps, and dis-coordination in care." Engeström does not describe the theory in his published works as explicitly as Kari Kutti does (1991). I use Kutti's description of Engeström's model as it is adapted to understand the activity system model (Kutti, 1991). He defines the subject in the model as an individual, or a selection of individuals or collective of individuals. Kutti (1991) recognised the central relationship within the activity system as between the subject and object. This relationship is communicated via a tool like for example technology, but may also be communicated by abstract tools like knowledge or questions according to Engeström. Kutti states that every tool has a story. Humans' interactions with the world are mediated by tool(s), thus the tool will influence the way humans interact with the world, and this influence is culturally developed over time (Kutti, 1991). Kutti (1991, p 256) further emphasize that using activity theory to understand work, requires the mediation to be goal orientated human action, in which humans relate to the objective world as well as human culture and history. He acknowledges that the community mediates the same object. Engeström by this adds two new relationships: the subject - community relationship, and the community – object relationship.

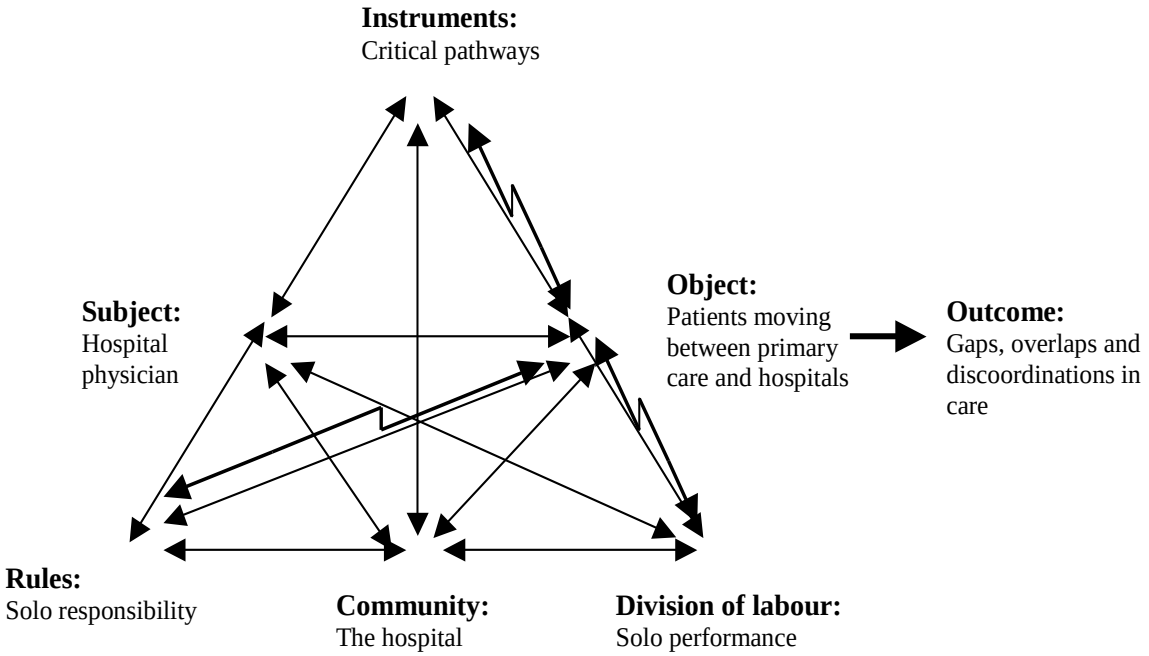


Figure 16: Engeström's model showing contradictions in the activity system of a hospital (Copyright: Y. Engeström, 2000)

Engeström recognizes the relationship between subject and community as mediated by rules, and the relationship of the community and the object mediated by division of labour (Kutti, 1991, p 256). He argues that both these mediations are historically shaped and open possibilities for further development and changes. An important aspect of Engeström's model is the duality of the subject and object (Kutti, 1991, 257). Engeström states that the subject influences the object, while at the same time the object will influence the subject, since the properties of the object will transform the subject. A weakness in Engeström's model, which is pinpointed by Fitzpatrick, Tolone and Kaplan (1995, p 5), is the undefined process in which the community of actors articulates actions. They argue that the reason for this may relate to the fact that historically activity theory has a more individualistic perspective on work activities. For a deeper dive into the foundations of this theory, a throughout reading of reference literature is recommended, see especially Kutti (1991) and Kaptelinin & Nardi (2006).

3.4.3 Interview #2 analysis: Trajectory mapping

Using activity theory, the participants' health information activities were identified, and analysed further in relation to appearance in time and place. Thus, it appears natural to map the participants' activities within the thoracic surgery trajectory, such as during pre-surgery or surgery/hospitalization or post – thoracic surgery. The standard thoracic surgery trajectory was used in this process, and adjusted to the individual participant trajectories. The trajectories are displayed as flow charts. In addition, the activities within the trajectory were organized into categories related to types of information source, e.g. medical record content; oral information; and standard patient information / material.

4 RESULTS

In this chapter, the two participants are first presented. Next, a description of the data from the repeated face to face interviews are presented. These data include a paper-based prototype feedback; identified and mapped activities within the patient trajectory; and an experimental patient design of timeline view (with medical record information; visualization and other relevant objects considered useful for the participants).

4.1 Interview #1: Patient perspectives and feedback to mock ups

It is necessary to make an individual description of the two patient's participating in the study in order to understand their perspectives as they entered and traversed the trajectory, as well as the events that they emphasized during the interviews. The presentation is based on two interviews with the participants as they memorized their individual trajectory. The interviews were primarily based on the case study. In addition informal conversations was an important source of information, as both patients, on their own initiative, communicated their personal patient experiences before the questions from the case study was addressed. After presenting the interviews, a summary of the patients' responses to the case study are structured and described. The results from the case study are useful in comparing the gathered data to the standardized questions. The information presented in this paragraph is later extracted and organized in line with Engeström's activity system model (see table 16 for overview and details).

4.1.1 Participant A's story

Participant A is a woman of age 42. She has a congenital heart failure, as was born with a hole in her heart. She has three children. After staying home with her last newborn, she experienced unusual exhaustion and tiredness. She felt that something was wrong, but could not point to a specific cause. She has previously associated her tiredness with the typical fatigue that comes with being a mother to three young children. As she was planning to go back to work, she visited her regular GP to get her condition examined, and to check whether it could be connected to her congenital heart failure. Her regular GP referred her to the local hospital. The local hospital made their assessments, which included ultrasound of heart and ECG. Subsequently, the local hospital referred her to the regional hospital. In the regional hospital they did a cardiac catheterization and tested her heart under work load while monitoring her (ECG). In a first assessment, the healthcare providers at the regional hospital evaluated her case as not suitable for an aortic valve replacement. She complained and made them do a second assessment. After the second assessment she was accepted for an aortic valve replacement. In December 2005, she was hospitalized at the regional hospital and the aortic valve replacement was performed. She said she was told that this type of heart surgery was considered a routine procedure. None the less, she knew that the procedure and the open-heart surgery itself included a relative risk. The outcome of the aortic valve replacement was not a success for her. After a critical post-intensive experience, she was transferred from to her local hospital in a serious health condition. She ended up with an internal pacemaker, and

depends on daily medication including a blood-diluted drug called Warfarin. Thus, the participant is particularly interested in her medical record content from the year 2005, in order to read about the circumstances surrounding the unsuccessful thoracic surgery. Her perception is that the providers at the regional hospital did not want to cope with the unsuccessful surgery. She says that after the surgery, when she was being monitored, she passed out several times. The reason being that her heart rhythm was irregular, and that the intervals between heartbeats were too long. The doctors at the thoracic surgery department claim that this is not normal; and is not supposed to happen. Furthermore, participant A experienced a discharge pressure from the doctors at the regional hospital, as well as a desire to transfer her to the local hospital, which is a regular procedure in standard surgery trajectory. In her words the intensive-care nurse at the regional hospital's intensive care ward was standing up for her, in her severe health situation. She thanks her nurse's persistence for her survival. This particular nurse requested the doctors at the regional hospital to take the situation for what it was, a life threatening situation. As a result of this she was granted an extension of several extra days in the monitoring room, and her exterior pacemaker was not removed, contrary to what the doctors first insisted on. The participant experienced her doctors as being doubtful about her keeping the exterior pacemaker. She thinks the reason was that the equipment was expensive. The doctors expressed the view that if she took the device with her to the local hospital, they probably would not get it back. End of the story was that after an extended intensive care period at the regional hospital, she was returned to the local hospital by airborne ambulance. On reaching the local hospital, her heart rhythm was once again irregular, and she passed out. In the rush of arrival, she has to go through new surgery at the local hospital. During this procedure the local surgeons connected an internal pacemaker to her heart. She expressed great interest in reading about these events in her medical record. In addition she expressed an interest in information about the follow-ups since she might soon be entering a new trajectory. Participant A conveys that after the unsuccessful surgery she was given three options for future treatment: 1) Re-doing the aortic valve replacement, 2) A wait-and-see approach, meaning continuing with the blood diluting drug and the pacemaker, 3) Heart transplantation. During her first follow up control at the thoracic department's policlinic, the doctor in charge and participant A agreed that re-doing the aortic valve replacement would not be a feasible option, given her state. Today she is coping with the diagnosed heart failure, while still being dependent on her pacemaker and the blood diluting drug. She undergoes annual controls at the regional hospital, where heart specialists make assessments with regard to future patient trajectory. Her diagnosis has recently been altered in her medical record, whereas the earlier

diagnosis was “aortic valve replacement”, she now has the diagnosis “heart failure”. The change of diagnosis appeared to her as new information, which she first became aware of as she was reading her copy of the medical record. In her opinion the doctor should have informed her about the possibility of a new trajectory. She has acknowledged that her only treatment option at this point is a heart transplant. However, she hopes she can postpone the transplantation for as long as possible. She argues that heart transplantation involves great risks, and she worries about the outcome. In her opinion survivors are either getting a totally new life (significant improvement in the quality of life), or stay sick / does not get any improvement in health. Being a mother of three children, and dealing with such prospects is not an easy situation. She says that her health condition as it is today affects her daily life, as she gets exhausted when performing normal activities like cleaning the house. If she engages in normal leisurely activities, like a course in weaving (as she was the weekend I met her for the initial interview), she needs to include a couple of days extra in her time scheduling in order to rest. She is under 24/7 monitoring of her own health condition, because of an increasing risk of heart attack given her diagnosis of heart failure. She considers herself as an active patient in interactions with her healthcare providers. She expresses an interest in being an empowered and knowledgeable patient, and organizes her own medical records in binders. During consultation she asks questions like “What does that mean?” or “Please, explain to me what you are seeing”, and so on. Furthermore, she keeps track of her children’s medical records. She is particularly concerned about the medical records of one of her daughters. This daughter has a very rare disease, which requires frequent healthcare consultations. The participant seems experienced in interacting with healthcare providers when she mediates on her own as well as a mother to her child. She sometimes asks for the patient summary after admission to hospital. At the same time she says the she’s got a feeling that this requires extra work on behalf of the healthcare providers, and that in some cases such requests are considered demanding and troublesome. She says that she has never has seen her entire medical record, but that she knows that her record as a whole is a heavy bunch of papers. Her experiences includes travelling from south to north in Norway, in order to meet a specialist for a second opinion, whereas her request about forwarding accurate and updated medical record from her regular hospital has failed to materialize. As a result the specialist based his second opinion on outdated (seven years old) x-rays (which was hardly a source for accurate knowledge). In her opinion, permitting her to copy own medical records would allow her to convey accurate documentation to other health providers. In this way she would not have to depend on others doing their job. In situations where her daughter has undergone health

controls the participator has also experienced a lack of information between health providers. She gave one example: when her daughter was undergoing an important control at the University hospital in Northern-Norway (UNN), x-rays in possession of the local hospital was not sent to UNN. As a result outdated x-rays from 2004 were used as base for the control at UNN. Participant A was very upset about this routine slip. She was saying that if she had copies of all the records herself, she could easily send over the x-rays herself, or bring copies. That way she would not be depended on others doing their job. In a similar vein, she emphasizes that information about what is going to happen during consultations is important for her, as knowledge about this could contribute her mental preparations for upcoming procedures. She is aware of the difficulties in providing exact information about what is likely to happen in a future consultation, but nevertheless thinks that the healthcare providers probably know the main objective in an upcoming consultation. Another aspect is her interest in features like administration of patient journeys that can be added to the new technology. In particular she takes an interest in features like management of bookings of patient journeys and travel refunding. E.g. when receiving letter with scheduled time for follow-ups, the letter (as mention above) seldom contain information about which issues are going to be the objective of the consultation. Furthermore, the letter contains imprecise information like "consultation is set to last from 1 to 3 days". The lack of precise information makes it very difficult to book train tickets in advance, and to plan how daily life at home should be settled during her travel. When getting patient travels refunded you are also required to select the cheapest travel alternative. She says that if she knows the main objective for her follow up, she could – based on previous experiences – probably estimate more precisely the number of days it would take. Therefore she often calls the hospital to check the objective before booking travels, though sometimes she does not bother to make this phone call. In the latter case she just has to wait and see. She expresses a wish that the new technology could clarify the main objective of a follow up, or give her access to an easier communication tool for information exchange. Instead of calling the policlinic it would be practical to just send them an e-mail. She also makes statements about including features into PHR that makes it easier to exchange travelling documents between her healthcare providers and the unit of the hospital responsible for patient travel refunding. The reasons for being that in order to get travels refunded by the national insurance, one needs confirmation from the healthcare provider that the trip was a necessary, and that she actually appeared on the set appointment. This confirmation has to be sent by her to the hospital's patient refunding unit located in Skien. Thus, it involves the exchange of several signed documents, and significant time-lags before

the money is finally refunded. This is time-consuming work and could be done more efficiently and cheaper by electronic information exchange using PHR.

4.1.2 Participant B story

Participant B in is a male of age 72. He has gone through an emergency - so-called unscheduled - aortic valve replacement in the thorax surgery department. He got ill a Saturday evening after a nice dinner and a nightcap. The heart / chest pain symptoms were a very uncomfortable experience. He is a tough man, and went to bed despite the present symptoms. He waited until Monday morning before he went to his regular GP. The GP sent him directly to the local hospital for further examination, where he was immediately assigned as an inpatient. The assessment included ultrasound of the heart and ECG monitoring. The sudden hospitalization surprised him, since he thought the hospital consultation would only be for additional examinations. From the local hospital he was referred to the regional hospital, where they did a cardiac catheterization. The doctors expressed the opinion that he needed immediate surgery.. Nevertheless he was able to delay this for couple of days, arguing that he needed to arrange some issues at home prior to a longer term hospitalization. None of the doctors at the local hospital were able to inform the patient about the upcoming surgery, or the type of aortic valves to choose from. The loss of available information was stressful to the patient that transformed from a healthy person to a person in sudden need of life saving surgery from one day to the other. He called the surgeon at the regional hospital from his home residence to get information about the surgery, and about his choice of aortic valve tissue. Together they arrange a meeting to be held as soon as he arrives at the regional hospital. When arriving Sunday evening 7th December 2009, the day before surgery, none of the surgeons were on duty. He is left with a lot of unanswered questions that has to be addressed before a decision can be made. As he points out, when acquiring new knowledge and information, new questions are generated based on upgraded skills, and these questions also needs to be answered. His dilemma is whether to choose a mechanical or biological aortic valve material. Both materials involve pro and cons in use. The mechanical valve is hard-line and has prospects of lifelong duration, but it also requires the patient to take blood-diluting medication for life. By replacing the defect aortic valve with a biological valve (taken from an animal), he will not have to take blood-diluting medication. The drawback is that the biological aortic valve only lasts for 10 to 15 years, and which it has to be replaced again. He understand that he is in the grey zone, since his surgeon has told him that if he was five years younger, mechanical tissue would be first choice. Younger persons do not have the option to

choose between mechanical or biological aortic valve, they get a mechanical aortic valve without discussion (with some exceptions). The reason is that if they had chosen a biological valve they would have to re-do the aortic valve replacement surgery every tenth year. A 40 years old person would then have to undergo at least 4 aortic valve replacements on average, which would not be an appropriate allocation of scarce resources. Participant B tells that met a girl doing early rehabilitation, and he had asked her which type of material her aortic valve had been replaced with. He was surprised to learn that the girl did not know which kind of valve she had got. His concerns are well founded, since within 10 to 15 years he wouldn't know if it is him or the aortic valve that retires first. What if the biological aortic valve fails in his early eighties, while he stills feels like there are many good years ahead? Re-doing an aortic valve replacement at high age induces several risks and problems. The decision he is about to make has a significant bearing on his future. To get the information he needed from the responsible surgeon, he had to call the surgeon when he was off duty. In his opinion the surgeon was very professional, and managed to highlight pro and cons for both options, even if he understood that the surgeon himself would recommend the mechanical aortic valve. In the end of the phone call they decided to meet the next morning to make a final decision. 30 minutes before the surgery they got together for a meeting. Since the meeting takes place immediately prior to the upcoming surgery, they have to postpone the "indifference" injection. The patient is of clear minded during their conversation. In the course of the meeting, the patient decides to choose the biological tissue. The decision is made under significant time pressure. Still patient is satisfied about his active participation in own health care. He says that in such a serious decision he has to be included and take a conscious standpoint so as to avoid regretting being a passive object after the operation is finalized. He said that in addition to weighting pro and cons that he also has told the surgeon that he had to inform him if his choice was absolutely crazy or in conflict with recommendations. The surgeon responded that if he (the patient) had been five years younger or older, the conversation would not have been necessary, since the choice in that case would have followed a rather standard procedure. The surgeon also said that future developments within heart surgery and aortic valve replacement are promising. There are several trials for a procedure called valve in valve implants via catheter. This procedure includes replacing a failing artificial animal based heart valve by implanting a mechanical valve inside it. This is considered to be an especially promising and effective option for patient at high risk, since the procedure can be carried out without need of open heart surgery. Based on the two phone calls with the surgeon and the last minute meeting before surgery, Participant B decided to

choose the biological tissue for the aortic valve, even if the surgeon recommended him to go for the mechanical material. After he had taken the decision, the surgeon supported him fully in his decision. The decision making process was his major patient experience from the thoracic surgery process. With regard to the decision he made, he says that he still does not know if he made the right decision – and that only time will tell. However, he also says that he is glad he opted for the biological tissue since this releases him from a lifelong relationship with Warfarin. He also expressed trust in the surgeons at the regional and local hospital, stating that "all in all they do a great job". He also stresses the that in his meetings with doctors he often had to urge them to talk Norwegian and to write in Norwegian. Often he has experienced that doctors uses Latin phrases consistently, which does not make sense to him. The doctors writing skills, and the way they formulate phrases in the medical documentation does not impress him either. He has read own records during hospital stays, and the statements in these records have no meaning to him. He also adds that in his experience healthcare providers in his local hospital have lots of new high techs equipment that they are not trained to use. He was surprised when he realized that they had to embark on a repeated trial and error process to learn how to handle the equipment properly during examinations involving him as an object. He says that sometimes they just gave up and went back to older versions of the same equipment. The participant requested information during all the phases along his trajectory. In his experience doctors express informal information with no follow up explanation. By doing so the patient is left to his or her own interpretation. E.g. the local doctor said to him during the examination that his aortic valve was reduced to a third of normal capacity. The participant did not respond to this information, but he got really anxious since "a third" made him think he was in serious trouble. After the surgery, when he reviewed information about heart illness, he found that a third of normal capacity is not the worst case scenario. Symptoms of a reduced aortic valve function often appear when the capacity is reduced to about a third, so a third is only an initial phase of a more serious heart failure. Had known this at the time of his hurried decision, he might have considered postponing the surgery.

The final sections I present a summary of the gathered case study data from the interviews part I and part II.

4.4.3 **Feedback to questionnaires and mock ups design**

None of the participants were technically advanced and savvy users, but they were both comfortable in administrating a personal computer, as they own laptops and have Internet access from their homes. They both use Internet on a weekly basis. Only one of the participants was handling financial affairs by online banking, these affairs were conducted by the spouse and not by the participant herself. Both participants were reporting annual taxes through online services either by themselves or with the support of a close relative. Even if none of them were active online service users themselves, they both expressed a positive attitude to the opportunity of accessing own medical records by a web-based system. They have both been accessing own paper-based records, but only one of the participants – participant A – were saving medical documentation (mostly patients summaries) for later use / re-use. Participant A was saving these records also had developed a binder that could be compared to a paper-based PHR. This participant was saving the record for quality assurance and to be updated on own health. In contrast, participant B did not save any medical record and states that if any record is needed "I will go to my GP to get a copy". This participant had only read the medical record on occasions when the patient summery was handed to him on discharge from hospital. Participant A, that received scheduled surgery, was satisfied with the patient's information received in advance of surgery. However she was not satisfied by the information received after surgery, as she was scheduled in a hurry for a new surgery after being discharged from the regional hospital. Participant B, that had acute surgery, was in a situation of stress in relation to getting timely information for decision-making ahead of surgery. He also missed general information in the entrance of the trajectory, probably caused by the short time interval and acute situation. Both participants experienced information gaps as a result of fragmented healthcare services when moving from local to regional hospitals for assessment, and regional to local hospitals for surgery. Participant A experienced a lack of relevant information during the thoracic surgery process, and stated that "sometimes information on procedures or plans underlying consultation requests (written, sent by mail) are left out, like the questions why, what, how". She further argued that more information about planned activities on a day-to-day basis during hospitalization would make her more comfortable. In addition, she had experienced an unsuccessful thoracic surgery, and is still wondering about issues related to this surgery. Both participants have contributed required information to their healthcare providers when asked to. Only one of the participants has controlled that the provided information was actually received and noted by the healthcare team. The other participant seems to trust the healthcare provider to a greater extend. Both

participants felt that they were actively participating in own healthcare, and that they shared the responsibility with their provider when healthcare decisions were made. For example, one participant has entered into an agreement with healthcare provider not to re-do the unsuccessful aortic valve replacement. In addition, one participant had chosen to replace his aortic valve with a biological aortic valve, even if the surgeon recommended a mechanical one. The participants were asked, “What health information did you get as an out-patient?” The female participant said that after the unsuccessful aortic valve replacement, she did not get copies of the medical record, but that the papers were sent to her local hospital. The male participant said that he got some papers, but he was not informed about the pain that could be present after the surgical operation. This lack of information resulted in rapid follow up consultation, since he experienced intensive pain in the chest region. This pain is normal in view of the open surgery undergone, he was told by the healthcare providers. In relation to access of own medical records, and informational needs the patients were invited to make additional comments about these issues. Participant A said she has lots of experience of health providers and communication. She often ask herself "What are you doing know", "Why are you doing this", "What does this mean" during consultation and procedures. She further claims,”… by being an "active" patient, I get relevant information. If I don't ask, they (both doctor and other health personnel) do not necessarily tell. Often they start empty talking.“ She once experienced a situation in which the healthcare providers were talking about holiday plans during cardiac catheterizing (in her vein), and failed three trials of catheterizing. Though, when she started asking technical questions about the procedure this made them focus on their task. The acute case participant said about a similar context that “I missed information before having my surgical operation, but this might be a result of my acute health situation.” He further complains about the doctor language and say “that they have to learn to talk Norwegian, otherwise we (patients) are not able to understand what they are saying”. He emphasizes that when talking to the surgeon at the regional hospital he was really impressed about the way the surgeon presented the information to him. He stated that the surgeon probably was an attractive lecturer within his medical field, since he had habitually expressed complicated medical knowledge in ways that lay persons could comprehend. He also felt that the surgeon actually enjoyed being asked these questions, and that he talked about his topic with passion. He experienced the opposite in the local hospital, where the doctors responded him with “you ask to many questions”, “sorry, I do not have knowledge about thoracic surgery”, “you have to wait and ask the healthcare providers in the regional hospital”. The

brochures about heart failure that he got in the local hospital contained information that deviated from the information he got in the regional hospital.

The attitudes of the participants were that the paper-based PHR seemed useful and promising. They both appreciated that the nature of such a tool could be helpful for them as patients. Furthermore, they both got several ideas just by looking at the limited sketches of possible features. Participant A was concerned about the structure in relation to how the information was going to be presented. She suggested that the information should be presented as a whole with all events together, in addition to filter views for specific events or object such as procedure, treatment, event/time, doctor/surgeon or hospital, with more. Participant B fancied the timeline view and said it made sense for him to organize events by time. He expressed that he would like options for overview of relevant information, which would allow him to navigate further into the structures in order to obtain extended information. He also expressed a preference for organizing information graphically, e.g. display lab test results by time. When asked what kind of information was most important to them, both replied “access to my records is of main importance”. However, participant B added that if he was going to access the medical record he would need support in reading them. He stated that a knowledge source for medical terms could be useful to him. Participant As main concern was structure, and how important that was for easy navigation. She also recommended features that: could support her with social services; ease the refund of travel money; and help her find relevant information and explanations of procedures or tests taken. She expressed a preference for a colourful website, simplicity and ease of navigation. She liked the icons (e.g. like the journal icons illustrated as maps, instead of textual layout). Furthermore she suggested options permitting printing of medical record for re-use when seeking other providers than the record's originator. Participant B preferred simple designs and added that it had to be “clear or obvious what I have to do to achieve desired tasks”. He requested that small icons or texts should be avoided, since they are hard to read. Both participants would like to make own notes in the PHR. One of the participants responded that the notes should not be in the original medical record, but rather in a separate space for personal notes. The other participant said that an option for making comments to the medical record would be useful. These comments ought to be printed so that they were available as a support of own memory in interactions with healthcare providers.

In the end they were invited to grade PHR functionalities based on usefulness on a 1 – 10 scale, with '1' =“Not at all important”, and grade '10' =“Very important”. The results of the grading are sorted below on average grade in descending order.

1. Participate in research projects **10**
2. Medical history **9**
3. Patient summary / discharge note **9**
4. Lab tests **9**
5. Make new appointment online **9**
6. Record log (who have accessed my record) **9**
7. Medication overview **8**
8. Allergies / cave **8**
9. Alert before doctor appointment **8**
10. Access to medical knowledge source **8**
11. Renewal prescription **8**
12. Vaccine overview **7**
13. Making own notes **7**
14. Rehabilitation plan **6**
15. Communicate with other patients **6**
16. Alert / risk profile **6**
17. Communicate with providers **6**
18. Update contact information of relatives **5**
19. Vital measures **5**
20. Online health shops **5**
21. Share information with relatives **1**

As can be seen, they grade participating in research studies as their number one, meaning that they find this functionality most useful, compared to the rest of the listed functionalities in a future PHR. The second most useful feature(s) is access to medical history, patient summary, lab test results, making new appointment with healthcare provider online, and to view the record log that displays who has accessed their medical record. The feature they found least useful was sharing medical record information with relatives.

4.2 Interview #1: CHAT results

4.2.1 Activities

The participants' health information activities that are extracted from the gathered interview data can be organized according to the components included in Engeström's activity system model (with regard to subject, object, and community). Figure 17 displays an overview of the 24 activities carried out by the participants.

The participants evaluated the activities during the final follow up interview to assure the data quality. Ideally, all the activities should been drawn as models, but due to space and time constraints, only a few selected activities are illustrated in the end of chapter four.

Systems	Components	Description
Activity 1:	**Action**	**Patient asks the doctors in the local hospital questions prior to having surgery**
	Subject	Aortic valve replacement patient
	Tool	Questions asked about surgical decision
	Object	Doctors at local hospital
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Health providers at the local hospital (nurses, doctors), patient, Health providers at the regional hospital
	Division of labour	Patient needs to make a decision, health care workers are responsible for informing the patient about available aortic valve material to chose
	Outcome	The patient has to wait until he gets to the regional hospital to get knowledge needed for decision making
	Motivation	Decision making
	Information source	Oral information
	Design consideration	In box for standard patient information on aortic valve replacement issues and surgical procedures Test results and notes from the latest consultation where doctor suggests thoracic surgery Access to relevant statistical information of aortic valve concern Access to social networks, like networks of other thoracic surgery patients
Activity 2:	**Action**	**Patient asks the regional thoracic surgeon questions by phone the day before surgery**
	Subject	Patient scheduled for aortic valve replacement
	Tool	Questions, telephone
	Object	Thoracic surgeon from the regional hospital
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Thoracic surgeons at the regional hospital, administrative staff and other health care workers at the regional hospital

	Division of labour	Patient needs to make a decision, health care workers are responsible for informing the patient about available aortic valve material to chose
	Outcome	Patient gets the information he needs about the pros and cons of the different aortic valve material for decision making
	Motivation	Decision making
	Information source	Oral information
	Design consideration	See design consideration at activity 1.

Activity 3:	**Action**	**Patient reads consultation letter ahead of post surgery consultation**
	Subject	Patient
	Tool	Consultation booking system, letter
	Object	Information in consultation request letter
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Official regulations and health laws, documented work practice guidelines
	Division of labour	Consultation coordinator, responsible doctor, patient and other health care workers at the regional hospital
	Outcome	Patient lacks information including in the consultation letter, e.g. its duration, planned examinations with more
	Motivation	Knowledge, mental preparation
	Information source	Standard patient information letter and brochure sent by snail mail
	Design consideration	Inbox for consultation request letter following standard tests regular taken and procedures with regard to test results

Activity 4:	**Action**	**Patient stores discharge / patient's summaries**
	Subject	Patient
	Tool	Binders
	Object	Discharge summary
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Surgeon, administration staff
	Division of labour	Patient gets discharge summary by mail sent from health provider's institution
	Outcome	Discharge summaries are organized in a binder
	Motivation	To keep for later re-use, quality assurance, knowledge
	Information source	EHR, Patient summaries
	Design consideration	Discharge summery storage sort by time with filter options of elements in thorax surgery trajectory e.g. doctor, hospital, procedure, medication, tests results

Activity 5:	**Action**	**Patient asks for copy of discharge summary**
	Subject	Patient
	Tool	Question, form
	Object	Surgeon, nurses
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Surgeon, nurses, admin hospital staff
	Division of labour	Patient make contact with health provider for copy of discharge summery – administration staff print copy and send copy per mail or hand it over physically
	Outcome	Patient access own medical record to keep herself updated
	Motivation	Knowledge, quality assurance
	Information source	Oral information

	Design consideration	Send request to health provider (Outbox) including address registry of health providers

Activity 6:	**Action**	**Patient asks for information about a specific test procedure**
	Subject	Patient
	Tool	Knowledge
	Object	Surgeon, nurses, bio engineer
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Surgeon, nurses, bio engineer, institution
	Division of labour	Health provider should give patient information ahead of test procedures
	Outcome	Patient gets information ahead of test to be prepared and informed
	Motivation	Knowledge, mental preparedness
	Information source	Oral information
	Design consideration	Electronic access to info base that includes test procedures / clinical guidelines

Activity 7:	**Action**	**Patient fills out standard schema about problems, symptoms and medication with more**
	Subject	Patient
	Tool	Knowledge, assessment
	Object	Surgeons, nurses
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Admin staff, surgeons, nurses, institution
	Division of labour	Patient fills out a standard schema sent by mail pre-surgery about problems, illness history. Healthcare provider uses patient-report in assessment and report updated info in clinical meeting and add the patient own – report to patient's medical record
	Outcome	Patient give information to healthcare provider that is useful and essential for assessment and outcome of surgery
	Motivation	Knowledge, quality assurance, supporting healthcare providers with essential information
	Information source	Patients stored EHR and other documentation e.g. medication list, memory
	Design consideration	Option for filling out information form electronically and send to provider before hospitalization 'Diary' options to write symptoms or complications

Activity 8:	**Action**	**Patient checks medical records for updates and accurate information**
	Subject	Patient
	Tool	Knowledge and examination
	Object	EHR documents
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Patient, surgeons, nurses and other healthcare providers that have written in the EHR
	Division of labour	Patient has a right to access own medical record and check quality of information that is written by healthcare providers
	Outcome	Patient is able to access own medical record and correct errors for quality assurance, avoid potential errors in treatment
	Motivation	Knowledge, quality assurance
	Information source	Paper based EHR documents
	Design consideration	Electronically access to own medical records

Activity 9:	**Action**	**Patient discuss whether it is worthwhile to re-do an aortic valve replacement**
	Subject	Patient
	Tool	Knowledge, questions
	Object	Surgeon in regional hospital and doctor at local hospital
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Patient, Surgeon, doctor, regional and local institution
	Division of labour	Patient and surgeon/doctor discuss options based on assessment to decide future patient's trajectory.
	Outcome	Patient is able to make decision based on relevant information for future patient trajectory and prognosis
	Motivation	Decision making for future patient trajectory
	Information source	Oral information and assessment based on information from EHR
	Design consideration	Inbox for standard patient information on aortic valve replacement issues and surgical procedures Test results and notes from the latest consultation where doctor discuss pro and cons for thoracic surgery Access to relevant statistical information of aortic valve concern Access to social networks, like networks of other thoracic surgery patients

Activity 10:	**Action**	**Patient decides what type of aortic valve replacement to get – biological or mechanical valve**
	Subject	Patient
	Tool	Knowledge, questions, professional advices
	Object	Patient, surgeon
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	
	Division of labour	Patient should be informed by responsible healthcare provider to make decision based on available information that will concern future trajectory
	Outcome	Patient is able to make decision based on relevant information. The decision is not coincided with the responsible surgeon.
	Motivation	Decision making that influence future patient trajectory
	Information source	Oral information
	Design consideration	Inbox for standard patient information on aortic valve replacement issues and surgical procedures, including information about material to chose (pro and cons) Access to relevant statistical information of aortic valve concern Access to social networks, like networks of other thoracic surgery patients

Activity 11:	**Action**	**Patient monitors own health and is living with a threat of possible heart transplantation in the future**
	Subject	Patient
	Tool	Experience, knowledge, questions
	Object	Responsible doctor in regional and local hospital
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Patient monitors own health symptoms and discuss health issues with her responsible doctor in regional and local hospital. She has a red line to this doctor in potential emergencies. The local doctor has to discuss her health issues with regional expertise in cases where the local doctor needs additional guidance to help patients. Assessment done during annual follow ups in the regional hospital

	Division of labour	Patient has red line to local hospital doctor for acute emergency situation. The local doctor discusses issues further with the regional expertise in thoracic surgery. Involves both individual doctors across institutions and the institutions itself.
	Outcome	Patient lives with a heart that could possible collapse, she has to be on alert to symptoms and problems that appear and has direct line to healthcare provider for phone consultation or direct hospitalization
	Motivation	Knowledge, decision making for future trajectory, assess own health, to share information / observation with her healthcare providers
	Information source	Oral information. Medical knowledge sources
	Design consideration	Knowledge base about heart transplantation and how to live and be alert of symptoms that could be indication of possible development of heart attack. Access to social networks for persons with similar health issues Secure online communication with regional and local doctor in charge Home equipments to support monitoring objects of great concern

Activity 12:	**Action**	**Patient returns to acute post-surgery control/consultation**
	Subject	Patient
	Tool	Test procedures, questions, assessment
	Object	Surgeons at regional hospital
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Surgeon at the regional hospital , responsible doctor in the local hospital and the patient
	Division of labour	The patient return to unscheduled consultation in the regional hospital after referral from the responsible doctor in the local hospital. Includes both individual doctors and their institution.
	Outcome	Patient return to regional hospital since he is experience symptoms of heavily pain in chest / shoulder region. The symptoms are “normal” side effects caused by the open-heart surgery which include the chest bone are bent open.
	Motivation	Acute pain, need assessment by professionals
	Information source	Oral information from the surgeons doing the consultation
	Design consideration	In box for possible symptoms appearing post surgery Online communication with health provider Online sensory monitoring

Activity 13:	**Action**	**Patient receives information following surgery**
	Subject	Patient
	Tool	Information, questions
	Object	Surgeons, nurses
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	The patient’s surgeons and nurses included in both regional and local hospitals
	Division of labour	The patient is informed by the surgeons and nurses following awakening after surgery
	Outcome	The patient is informed about the outcome of surgery and the future trajectory
	Motivation	Knowledge that effects the future patient trajectory
	Information source	Oral information, patient summaries
	Design consideration	Access to surgery notes and other EHR content concerning surgery

Activity 14:	**Action**	**Patient asks healthcare providers about what they are doing while they are doing it**
	Subject	Patient
	Tool	Questions and observations
	Object	Surgeons, doctors, nurses, lab personnel and others doing procedures
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Surgeon with other healthcare providers interacting with the patient presents during procedures / examinations, included in the regional hospital and also local hospital
	Division of labour	Health provider and other staff should inform patient under procedure
	Outcome	Patient gets relevant information, that helps her keep calm during specific procedure
	Motivation	Get knowledge, and to stay calm during the procedure
	Information source	Oral information
	Design consideration	Access to standard patient information about the specific thoracic trajectory "package" including descriptions about common procedures -A standard feedback from sent to all outpatients via PHR inbox to evaluate patient experience and to improve or adjust healthcare services.

Activity 15:	**Action**	**Patient gets knowledge about healthcare providers lacking training and experience in using high tech equipment during medical procedures**
	Subject	Patient
	Tool	Questions
	Object	Healthcare providers at the local hospital
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Patient, doctors and nurses with other healthcare providers that do examination on the patients, which requires use of high tech equipment that they are, not train in using.
	Division of labour	The patient's ask healthcare providers about questions related to use of advance technical equipments since they act unsecured when dealing with high tech equipment
	Outcome	The patient is troubled by healthcare providers that seem inexperience with new high tech equipment
	Motivation	To check if the healthcare provider knows what they are doing, quality assurance
	Information source	Oral information
	Design consideration	A standard feedback from sent to all outpatients via PHR in box to evaluate patient experience and to improve or adjust healthcare services.

Activity 16:	**Action**	**Patient asks questions during a cardiac catheterization since the healthcare providers doing the procedure seem unfocused**
	Subject	Patient
	Tool	Questions
	Object	Surgeon and healthcare providers doing the cardiac catheterization
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Patient, surgeon, healthcare providers, regional institution
	Division of labour	The patient asks questions to the surgeon during cardiac catheterization to make the herself, surgeon and the rest of healthcare providers included in the procedure to focus on the task – since they seem unfocused and failed two times doing the procedure.
	Outcome	The third trial of cardiac catheterization succeeded as the healthcare provider were able to focus on the task. The patient was able to relax as well, which also contributed to a successful performance.

	Motivation	To get the healthcare provider to focus on their tasks, and to stay calm herself during procedure
	Information source	Oral information
	Design consideration	In box for standard patient information on aortic valve replacement procedures, including information about cardiac catheterization A standard feedback form sent to all outpatients via PHR in box to evaluate patient experience and to improve or adjust healthcare services.

Activity 17:	**Action**	**Patient tells the doctors that they have to talk "Norwegian" since he don't understanding what they say or write when using "doctor language"**
	Subject	Patient
	Tool	Information
	Object	Surgeon in regional hospital
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Doctors in general
	Division of labour	The patient's emphasize to his doctors that they have to talk his language to make him understand what they are telling him.
	Outcome	The patient is able to get the doctor to inform him in a way that is understandable to him.
	Motivation	Knowledge, understand the information content
	Information source	Oral information.
	Design consideration	Tools for translating content in medical record like sandbox to edit record content, features like thesaurus, and additional knowledge info base

Activity 18:	**Action**	**Patient gives updates to surgeon(s) first day of hospitalization**
	Subject	Patient
	Tool	Own knowledge and experience
	Object	Surgeon
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Surgeon and others of concern (health providers) that need accurate information about new problems and symptoms for assessment of further trajectory
	Division of labour	The patient is required to give information about issues to surgeon and other healthcare providers including the anaesthetist nurse
	Outcome	The patient gets time to update the surgeon on latest health issues concerning own health.
	Motivation	Knowledge, quality assurance, get adjusted healthcare service
	Information source	Information source
	Design consideration	A outbox to send requested information to the healthcare provider – Filling out the required patient own - report electronically by re-use of previous medical record content. Diary option – Use an electronic diary to write down problems and symptoms as they appear for memo Print option for printing updated and accurate medication overview from the PHR documentation content

Activity 19:	**Action**	**Patient asks the doctor if this treatment is suitable with regard to present drug use (blood diluted drugs)**
	Subject	Patient
	Tool	Questions, knowledge
	Object	The GP

	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	GP, responsible doctor in the local hospital, responsible doctor in the regional hospital
	Division of labour	The responsible healthcare providers in both the regional and local hospital is required to transfer necessary documentation to the patient's GP for continuous in care, for the GP to have knowledge to treat the patient in further patient trajectory. The transfer of documentation includes staff in both institutions that are responsible sending documentation to right instance. The patient also is required to give know information about updated health information if she cans. The pharmacist may also be responsible to inform about contradiction is she has information about blood diluted drug use.
	Outcome	The patient aware the GP about contraindications that might happen if the proposed combination of drug use is carried out,. The patient avoids a potential critical health situation.
	Motivation	Quality assurance, avoid contraindications and healthcare problems
	Information source	Information, knowledge source like "Felleskatalogen"
	Design consideration	Access to online "Felleskatalogen" to check possible contraindications when mixing other drugs with Warfarin Online communication with a pharmacist for professional guidelines

Activity 20:	**Action**	**The patient asks her provider to sent copy of medical record to external provider**
	Subject	Patient
	Tool	Question
	Object	Local institution administration staff
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Local institution administration staff, external doctor
	Division of labour	The patient asks the local institution administration staff to send over medical record to external provider
	Outcome	Patient does a second opinion at external doctor but lacks timely and accurate health documentation. The external doctor uses out dated information from prior consultation in assessment and evaluation.
	Motivation	Knowledge, to assure accurate information
	Information source	EHR documentation
	Design consideration	Print options for the medical records stored in PHR No edit option in the original medical record accessible in PHR, to make the record authentically

Activity 21:	**Action**	**Patients manually reads the paper copies of discharge summaries**
	Subject	Patient
	Tool	Skills
	Object	Stored EHR documentations
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	All responsible writers of the patient's EHR content, across different institutions that have provided the patient with healthcare and copies of EHR content
	Division of labour	The patient reads own medical records that are written by the healthcare providers involved in the healthcare of the patient.
	Outcome	The patient reads information and by this is able to be empowered as patient and re-use information to manage own health.
	Motivation	Knowledge, quality assurance, possible decision making, re-use information

	Information source	EHR documentations
	Design consideration	Medical record storage sort by time with filter options of elements in thorax surgery trajectory e.g. doctor, hospital, procedure, medication, tests results

Activity 22:	**Action**	**Patient asks surgeons to translate test results**
	Subject	Patient
	Tool	Questions
	Object	Surgeons
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Surgeon, nurses and lab personnel in the institution where the tests are performed
	Division of labour	The surgeon and other doctors in charge orders tests to be taken by the lab personnel. The nurses tell the patient that tests will be taken. The patient has to participate when the lab personnel takes the tests. The tests are analyzed and results returned to the patient's hospital post. The results and its meaning are asked for by the patient. The test result may involve changes in the patient trajectory.
	Outcome	The patient is informed about the test results and their meaning for further trajectory in healthcare. The test results is valuable information in further decision making process.
	Motivation	Knowledge
	Information source	Oral information about test result receipts included in the EHR documentations
	Design consideration	IT support when reading the test results content such as: -Reference value as a supplement to the specific test taken -Historical view or visualization of test results and its context if repeated measurements are present

Activity 23:	**Action**	**Patient asks surgeons "test" questions to check if they have received updated and accurate information from previous surgeon on duty**
	Subject	Patient
	Tool	Questions, knowledge
	Object	Surgeon(s)
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines
	Community	Surgeons and other healthcare providers involves in information flow and documentation in EHR.
	Division of labour	The patient asks the surgeon(s) test questions. Based on the surgeon(s) response she updates the surgeon with latest information about her condition.
	Outcome	The patient assures herself that the surgeon has got the information necessary for decision making and assessment in future trajectory.
	Motivation	Quality assurance
	Information source	Oral information that is or is not transferred into doctor's note in the EHR documentations
	Design consideration	Patient report symptoms and problems of present status by use of electronic web, ahead of consultation. The web form is included in the institutions EHR.

Activity 24:	**Action**	**Patient receives standard patient brochure about heart surgery**
	Subject	Patient
	Tool	Standard brochure
	Object	Surgeons, nurses, administration
	Laws	Unspoken norms, official regulations and health laws, documented work practice guidelines

	Community	Surgeons and nurses are preparing the patient for upcoming surgery by giving information about heart surgery. Includes the institution as well.
	Division of labour	The patient receives a standard patient brochure either by mail, during consultation or in other context in meetings with healthcare provider(s). The healthcare providers have a responsibility to inform the patient ahead of procedures. The patient need information to be mental prepared and for decision making a head of procedure.
	Outcome	The patient has knowledge about what will happen during the hospitalization.
	Motivation	Knowledge, decision making, mental preparedness
	Information source	Standard patient brochure
	Design consideration	Patient should have access to standard patient information about heart surgery as soon as possible when entering the TS trajectory. The step by step procedures along the trajectory should be presented to the patient in an overview, e.g. included in the PHR's timeline view together with the medical record content. The information should include the trajectory as a whole, from entering the trajectory, to the end of it. This to fill the information gap that is present in fragmented healthcare services. The information should in addition to the electronic format also be available in paper format. The paper –based information could have layout similar calendar view or filo fax format or just be put in a binder – so the patient easily can access it and find day/subject of interest during the hospitalization when the laptop might not be accessible or practical to use.

Figure 17: Overview of the patient's activities, structurated by use of components applied from Engeström's activity system model with following design suggestions to be included in the new technology

Figure 17 displays identified health information activities by the participant / patient. The reason being that the new technology is supposed to be the patient's information system.. Therefore the patient's work needs to be understood. When looking at the patient work from patient's perspective, the patient becomes the subject of the system. It should be emphasized that in parallel, other, not listed activities are performed by the healthcare providers. The object is commonly the healthcare provider represented by the doctor / surgeon, and the relationship between the patient and the healthcare provider is mediated by tools such as questions, knowledge, and schema with more. The relationship of the patient and the healthcare providers must be understood in relation to the community as they are a part of a bigger picture, such as the work team during the surgeon shift; administration; bed post; intensive care department; the hospital; other institutions, with more. The relationship between the healthcare provider and the community is mediated by the division of labour, while the relationship between the patient and the community is mediated by the norms such as laws and official regulations, work practice, professional norms of conduct, and clinical guidelines with more. The outcome of the activity is a result of these three relationships

interacting. Based on the system and the outcome that follows, I am locate the information source as it is today and make suggestions as to how this information could be applied in the new technology. Information should be applied in the new technology so as to support both the patient and healthcare provider with their informational needs, and to make the information flow faster between the patient, healthcare provider and within the healthcare institution.

As I tried to identify different information sources, I realized that to contribute to the patients informational needs, information has to be added to the medical record to deal with critical patient trajectories. Thus, the PHR needs to be supplemented with standard patient information for decision-making, and information gaps that appear during the thoracic surgery process needs to be filled. The standard patient information in the PHR is supplied by healthcare providers. Thus, work practice and routines of an institution is not available by Google or other medical knowledge bases. The production of the additional information material will require resources and effort from the healthcare provider. But the outcome of empowered patients may be worth the effort. There are several types of information sources that are available to the patients during or after the thoracic surgery process. Loads of information is generated in EHR, from the moment the patient enters the initial pre-surgery phase. This information is produced and used by the healthcare providers to coordinate and document care during pre-surgery, thoracic surgery and post-surgery phases. The patient does not have access to this information before he/ she is discharge, and in regular cases the information from the medical record with regard to doctor's note is not accessible until after the discharge. During the pre-surgery and thoracic surgery phases, the patient is only supported by oral information. However if he / she is signed up for scheduled surgery he/she will get a standard brochure sent by snail mail. This brochure contains detailed information about the thoracic surgery phase. Thus, a critical information gap within the brochure is the missing description of the main event, namely the surgery guideline and procedure. The brochure contains information from the initial phase as an inpatient, and continues until the patient is moved in his / her bed to the surgery room, from there on the information in the brochure continues to describe what happens after the surgery has been performed. The lack of information in the brochure should be clarified, for instance with respect to the way in which the surgeon will approach the surgery, and which procedures that are going to be carried out during surgery. This lack of information is probably a conscious choice of the thoracic surgery department to avoid scaring patients. However, patients who desire such

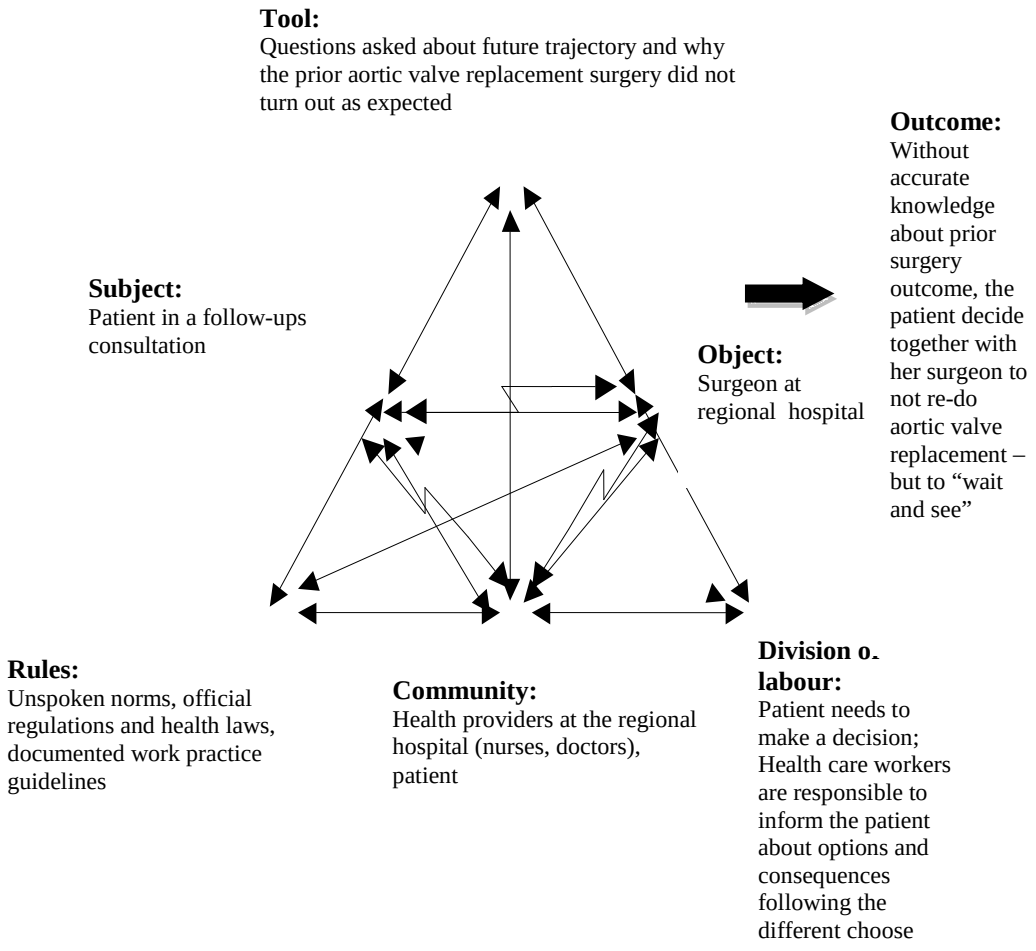
information should also be able to access it. Information about upcoming procedures is a tool that the patient can use in order prepare mentally for what they are going to go through, and to understand the surgery note that is written following surgery and included in the medical record. When the patient is informed about regular practices, he or she is better able to understand the likely results of what is done to them.

4.2.2 Contradictions - Information gaps

Both participants experienced problematic trajectories and huge information gaps during their thoracic surgery trajectory. Their experiences will now be sketched as activity system models according to Engeström's proposed framework, in order to analyse the outcome.

4.2.2.1 Activity system model: Participant A

Figure 18: There is a disturbance in the activity system for patient, since none have provided the patient with any explanation concerning the outcome of the aortic valve replacement. The patient needs to make a decision based on information available, despite the information gap in the activity system.



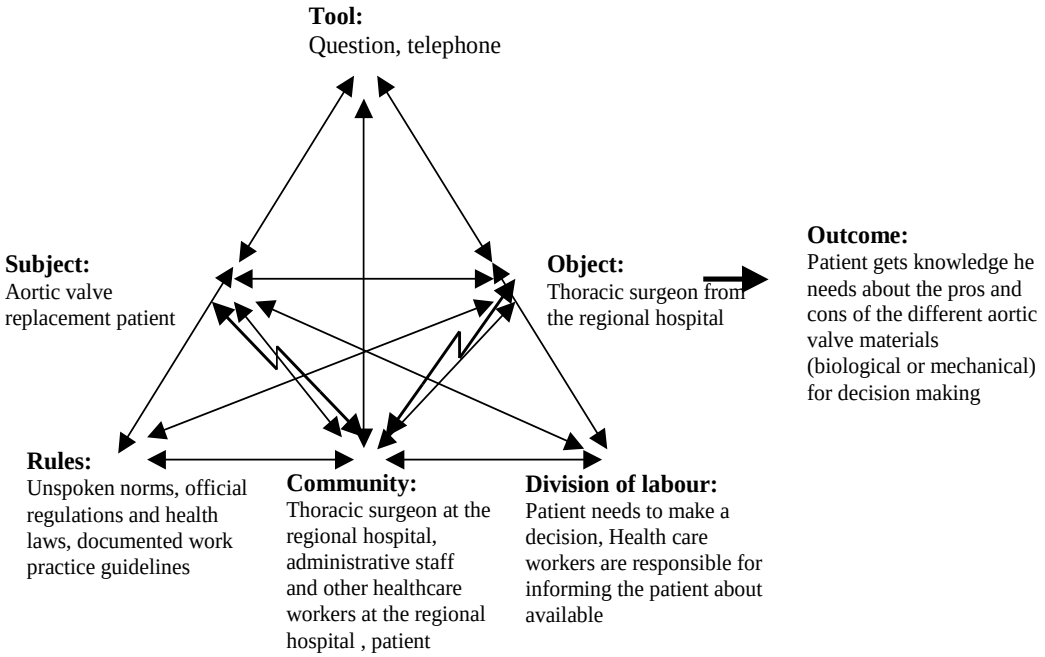
ACTION 9: Patient discusses whether it is worthwhile to re-do an aortic valve replacement

Figure 18 illustrates action 9 as performed by participant A (that had unsuccessful outcome of her aortic valve replacement). During her first follow up consultation in the regional hospital she had to make a decision about the future trajectory. Disturbances in three critical pathways of the activity system resulted in the outcome in which the patient made a decision based on incomplete information. First, the patient did not get an explanation from the surgeon about the likely causes of the failed surgery. Secondly, the information exchanged between the regional surgeon and local hospital was of poor quality, since the local doctors did not acquire information about the causes of failure in surgery. As the patient was discharged from the regional hospital and sent by airborne patient transport, the local hospital suddenly, and unexpectedly, received a patient that not only needed intensive care, but acute surgery. Third, the patient experiences of information gap may results from work practices and norms. Her mediation with the community is regulated by laws, as her lack of information and the realized outcome was said to be a case for a patient complaint.

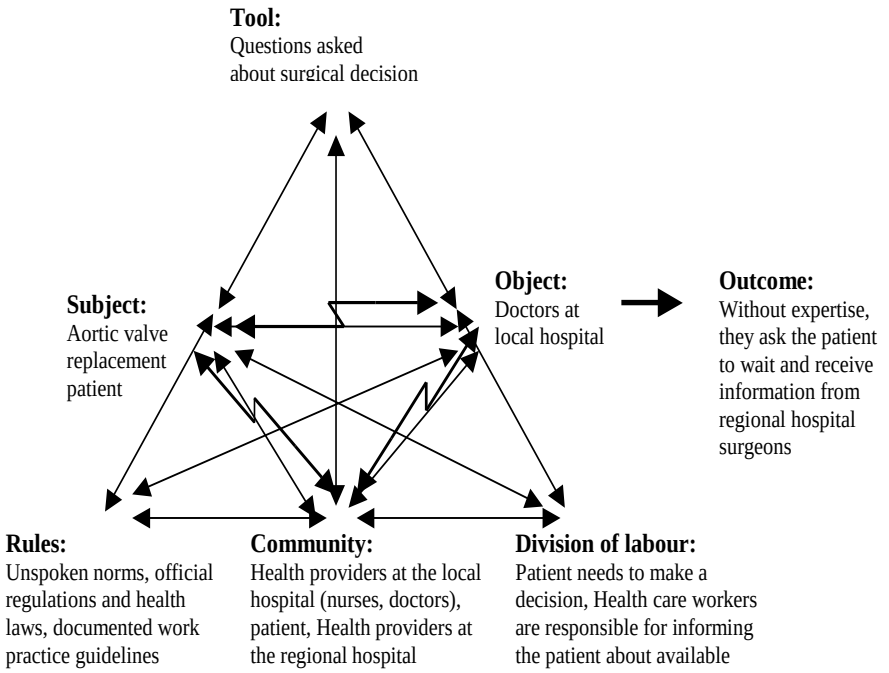
4.2.2.2 Activity system model: Participant B

Figure 19 illustrates action 1 & 2, performed by participant B. He suddenly became an acute case patient, and was scheduled for surgery. However, he struggled to make a decision on which aortic valve tissue to chose - biological or mechanical. Disturbances in two critical pathways of the activity system resulted in the patient scrambling to obtain information needed to make a decision on the day before scheduled surgery. The patient first asked for information from his doctors at the local hospital, but the doctors referred him to the regional hospital, stating that they did not have the information he demanded with respect to his surgery. At the regional hospital, he was told that the information was not available since it was Sunday and the surgeons were off-duty. The lack of information left him stressed and worried. As a consequence he started to reconsider the surgery. Thus, the patient was then given the private telephone number of his surgeon (since the planned surgery was set the following day), and was told to call the surgeon directly. This situation left the patient anxious until he was able to get in touch with the surgeon (who was skiing at the time). A disturbance is evident in the information handling of the healthcare institutions, and in the inability of anyone within the community to provide the desired information, except for the surgeon.

Figure 19: There is a disturbance in the activity system for both the local and regional hospitals, since neither can provide the patient with any information concerning valve replacement. The patient is filling the information gap in the activity system by calling the regional hospital surgeon off-duty the day prior to surgery.



ACTION 2: ASK THE THORACIC SURGEON QUESTIONS BY PHONE PRIOR TO HAVING SURGERY



ACTION 1: ASK THE LOCAL DOCTORS QUESTIONS PRIOR TO HAVING SURGERY

The outcomes produced by the contradictions identify problematic patient trajectories. In such trajectories the information gaps needs to be addressed, primarily by looking more closely at the healthcare institutions' work practice and information flow. Information gaps are to a large extent caused by fragmented healthcare services, resulting in fragmented health information. Action one and two illustrate how fragmented healthcare services can stress a patient that traverses the different institutions without getting timely information. Healthcare institutions are recommended to increase the information flow with respect to comprehensive standard patient information. The healthcare providers at the local institution seem to lack information about the thoracic surgery phase. In addition, local healthcare providers should have access to standard patient information provided at the regional hospital, or the whole patient trajectory including adjusted standard patient information. Furthermore, if a patient is admitted to a regional hospital on a Sunday, the regional hospital should make sure the patients gets to talk to a surgeon that is informed about the surgery scheduled on Monday.

The contradiction displayed in action nine could have been avoided if the patient got the opportunity to meet with healthcare providers from both the local and regional institution, and were given a debriefing or evaluation of the surgery phase. The information gaps could also be alleviated by support from the new technology. Possible design considerations are suggested in figure 17 above.

4.2.3 Activities and design suggestions

Based on the initial system requirements, the patients' health information activities, and the identified motivation and information source, design suggestions that are appropriate to include in a PHR for thoracic surgery patients can be made. Nonetheless, the sheer number of activities makes it challenging to get a full overview of the design. Several of the activities are also consider to be related to each other. For such reasons, I found it useful to group similar activities into activity groups so as to address process design more efficiently.

4.2.3.1 Decision making

A1: *Patient asks the doctors in the local hospital questions prior to having surgery*

A2: *Patient asks the regional thoracic surgeon questions by phone the day before surgery*

A9*: Patient discusses whether it is worthwhile to re-do an aortic valve replacement*

A10: *Patient decides what type of aortic valve replacement to get – biological or mechanical valve*

Activity 1 and 2 are closely related, since activity 2 is a consequence of activity 1. Activity 10 is the result of activities 1 and 2. Activity 9 is also related to decision making and lack of accurate information. These four activities are therefore discussed together. The patient is lacking essential information the day before surgery is scheduled. The patient activities reveal a critical patient trajectory within the system, since he is in the gray zone with regard to which type of aortic valve replacement material to chose. The existing standard brochure of thoracic surgery does not address his problem. The lack of needed information makes the patient insecure, and he wonders if he should cancel the surgery the following day. The activity is supported in the end, when the patient manages to get hold of and talk to the surgeon. This happens after he has puts pressure on head nurse, who finally arrange a telephone conversation between the patient and surgeon. After a constructive talk, and follow up meeting thirty minutes before surgery the patient is able to make a decision.

Verbal information is unstable in time and space, since verbal information is informal and likely to depend on the communicative skills of the person who delivers the information. Access to essential knowledge should be distributed as standard / formal patient information, and become a knowledge resource in the thoracic surgery department. The surgeons need to describe the typical information asked for in relation to aortic valve replacement, and address critical patient's trajectory. This patient is in a gray zone caused by his age, and is undecided as to the type of valve before surgery. He probably is not the first or the last patient in the thoracic surgery department confronting this issue. The surgeons should be motivated to write standard documentation covering this subject. They should also distribute it to patients that are in a gray zone, with remaining life expectancy from 10 or 20 years.

One of the participants confronts a major decision, as a result of an unsuccessful surgery. She says that during conversations with her doctor at the regional hospital, immediately after surgery, she made her decision not to re-do the aortic valve replacement surgery. Today she has reduced life quality. Her doctor has concluded that she has a heart failure, and therefore need backup support from an internal pacemaker as well as assorted heart medication, including blood diluting drugs. She says that her only option for treatment in the future is to

undergo a heart transplantation. She does not like to think about her health condition, and does not want to consider anew thoracic surgery trajectory, as this makes her uncomfortable.

New technology could support patients with a feature similar to a mailbox that includes incoming information from the health provider. One such piece of information it a standardized information form, which contains: (a) standard patient information about aortic valve replacement issues and surgical procedures; (b) the sections of the patient's health record including test results and notes from most recent consultation where the doctor gave reasons for the necessity of thoracic surgery; (c) statistical information on the different aortic valve replacement materials chosen by prior patients, for example expected lifespan after surgery an success rates in treatment; and (d) access to social networks, such as networks of other thoracic surgery patients, or a database with collections of patient experiences. Making this information available can prepare the patient for a conversation with the surgeon, and will help reduce anxiety. Making the information available also allow hospital staff to send it electronically immediately. This is desirable in acute cases.

New technology could also support patients with information with regard to unsuccessful aortic valve replacements, with the following trajectories and prognosis for the following three options:

1. Re-doing the aortic valve replacement
2. Medication
3. Medication and pacemaker
4. Heart transplantation

If statistical data are made available, the patient should get access to it via the PHR. Differences with regard to own health situation is probably the main constraint on the choice of therapy. Still, general and systematic information about the topic would be a better starting point for decision making than verbal and unstructured information from an individual healthcare provider. A challenge facing patients waiting for potential heart transplant, is that a patient has to be sick enough to be considered a candidate for another heart, and still healthy enough to have reasonable prospects of surviving the procedure.

4.2.3.2 Self – reporting health status

A7: *Patient fills out standard schema about problems, symptoms and medication with more*
A18: *Patient give updates to surgeon(s) first day of hospitalization*
A23: *Patient asks surgeons "test" questions to check if they have received updated and correct information from the previous surgeon on duty*
A24: Patient receives standard patient brochure about heart surgery

Activity 7 is closely related to activity 18, which refers to the patient giving updates of new knowledge and essential information to surgeon on the first day of hospitalization. Since the written and oral information coincides, the patient probably discusses or gives feedback to a report that has already been written. The information that the patient contributes is essential to the healthcare provider. It is the basis for assessment and management of the upcoming thoracic surgery. Activity 23 addresses the same issue as activities 7 and 18, but regards further information distribution within the organization. These three activities are discussed together. The healthcare providers have recognized that patients often lack the answers addressed in the standard schema and given to the patient ahead of surgery. The schema is sent by snail mail together with time and date for the scheduled surgery. In cases were surgery is needed emergently ("unscheduled surgery"), the schema might not be given to the patient before s/he has arrived in the regional hospital. In other cases the patient may have forgotten to bring along the schema to the hospital. Answering questions at arrival, when the patient is in stress for the upcoming event, may not induce the best memory with respect to own health condition. Activity 24 is closely related to activity 7 (the patient own report form), since the brochure is sent together with the form as a letter from the patient coordinator.

The new technology could support the patient with a feature similar to a mailbox including incoming information, sent from the health provider. This could be in a standardized web form which contains all the questions addressed to the patients in the paper based schema currently given to the patient ahead of surgery. Having the web form available at home prior to hospitalization allows the patient to re-use information stored in the PHR, such as prior medical records and medication usage lists, which will provide accurate answers to the questions addressed. When the web form is completed, it could be sent back to the healthcare providers prior to hospitalization. Completing the form enable patient's to supply essential and timely information to the hospital staff. The hospital staffs subsequently have to store the web form in the patient medical record, to make sure the information is available to everyone

that is involved in the care of the specific patient. In a similar way, the patient brochure that contains standard patient information should be accessible to the patient in the PHR. The standard patient information should be divided into pieces of information that is accessible in relation to different phases of the trajectory. The web form should be sent to the patients mailbox as well, as a copy and confirmation. The web form should also be made available in print format, so the patient can have his copy available during the conversations in the first day of hospitalization.

An important prerequisite to achieve such information exchange is that the web form and information is sent to the patients PHR immediately after signing up for surgery. This to assure that it is available for the patients' both in acute and scheduled cases.

4.2.3.3 Preparedness

A3: *Patient reads consultation letter ahead of post surgery consultation*

Activity 3 concerns the information needed ahead of upcoming consultation, in order for patients to be mentally prepared for the consultation. One of the participants points out that the notice sent by snail mail often includes only practical information, such as scheduled time and date, duration of stay, name of doctor and meeting place. When this participant turns up for the appointment, she expects a conversation about health status and some blood tests, but is not mentally prepared for a more thorough examination. Still, she has experienced the latter scenario, and perceives a need for including more details in the consultation notice letter. Probably some test results may lead to other tests being performed. Such follow up tests may in turn be difficult to assess prior to the consultation. Nevertheless, follow up consultations may have some pattern in the tests that are regularly undertaken, and information about this could be merged with the notice letter.

New technology could support patients with standard patient information, typically including tests taken during post surgery consultations. These should include routine tests that are regularly taken during post surgery examinations. In addition, the standard patient information should include information about tests that have been performed in cases were routine tests suggest the need for follow ups. The patient should also be supported by additional clinical guidelines from knowledge base source. Such guidelines include information about procedures and outcomes, and could empower patient, e.g. to by being mentally prepared ahead of consultation.

4.2.3.4 Health management

A4: Patient stores discharge / patient's summaries

A5: Patient asks for copy of discharge summary

A8: Patient checks medical records for updates and accurate information

A13: Patient receives information following surgery

A21: Patients manually reads the paper copies of discharge summaries

A20: The patient asks her provider to sent copy of medical record to external provider

All the listed activities include access and management of medical records and use of its content, or verbal information about surgery outcomes that is subsequently documented in the medical record retrospectively (the latter is activity A13). These activities are discussed together. Activity 8 and 21 can additionally be seen as involving navigation of information by going through the records for overview and search of subject of interest. All the activities relate to the core information within the system. Sources of information beyond the scope of the medical records are resources intended as supportive tools to enable understanding and re-use of the records content. These activities assume that medical records are accessible via the PHR.

The new technology should have an interface with the EHR system of the healthcare provider. A suggestion would be to automate the sending of information to the PHR server, by use of Norwegian health net and KITH's "Hodemelding" used for information exchange. The medical record could be reloaded automatically in the medical record storage, or the medical record could be sent by secure mail whereas the user of PHR stores the medical record in the folder for medical record. If the system does not have interface to a healthcare providers EHR system, the patient should have an Outbox for sending messages to healthcare providers, so that copies of medical record can be requested after consultation. The Norwegian Health net offers access to the address registry of healthcare providers, so finding relevant contact information would be an included feature in the Outbox functionality. Interface to healthcare providers EHR has been discussed in this project. Still, during the design access to health information is taken as given. In other words, the design and developed prototype take for granted that the user has access to own record via PHR. Managing relevant health information is the main concern in this thesis. Managing records is taken to mean the ways in which information is structured and presented to the user. Furthermore it includes information visualization and functionality for reusing of health information. Re-using the content within

the records in a manner that makes the information meaningful to the users is considered key functionalities in the information system. Design suggestions pertaining to information visualization of health information includes both standard patient information and the medical record. Since the main priority is to present overviews of relevant information, through sorting on time lines, it is suggested that the information be presented in relation to the phase to which it belongs (e.g. initial entry of trajectory; assessment; thoracic surgery; post-surgery and follow ups). The healthcare providers EHR systems are organized by healthcare professions such as doctors, nurses, physiotherapists, lab personnel, and so on. Thus, it is recommended that the patient PHR is organized as standard patient trajectories, separated into phases within the trajectory where information belonging to the specific phase can be linked by clicking the mouse, e.g. initial phase. The initial phase could then have links to the GP's note, the GP referral to the local or regional hospital, together with patient information such as information on suspected illness and information on the healthcare services commonly recommended in the initial phase.

A similar design of timeline visualization could also be used for extracting information related to a specific doctor, hospital, procedure, medication, test result and the like. This way of organizing information by use of a main timeline (including standard patient information and medical record) and further options using individual timelines to extract specific information of interest is thought to fulfil the individual needs of the participants, especially when it comes to the follow-up phase.

The records of the phases should not include an option for editing, e.g. writing own notes or deleting information users do not agree with. Nor should users be granted permission to re-write the contents of the record. Thus, the medical record should have read access only. The reason is that the user can use the print option and bring copies of records to other healthcare providers. The medical record content should therefore be authentic. The user should however be assigned a specific area for writing notes to the records. This functionality could be of comments type, similar to the web sites that have options for user to create comments to the websites content. In addition, the user also should have option allowing him or her to write an electronic diary: This will facilitate keeping track of daily symptoms and problems that need to be reported in the next meeting with the healthcare provider.

4.2.3.5 Self-monitoring

A11: Patient monitors own health and is living with a threat of possible heart transplantation in the future

One of the participants needs to monitor own health situation 24/7, since her aortic valve replacement was unsuccessful. She continuously fears that her heart will fail, but says that she tries not to think about it. She also says she has learnt to live with the fear and anxiety, and that she tries to cope with daily life as best as she can. New technology could support patients monitoring own health with regard to future trajectory. The wireless patient is monitored in his or her home doing every day activities, and the healthcare provider has access to the monitoring data. The wireless patient is thought to be a central part of future healthcare services. The healthcare provider is allowed to monitor essential indicators related to heart activity by the use of sensors for heart rhythms (ECG), blood pressure, oxygen saturation, weight etc.. Measures in curves and graphs could be easily transferred to the healthcare provider for decision making, e.g. in cases where re-hospitalization is discussed, or in situation when the patient is in doubt about how severe apparent symptoms are. Such data should be accessible to the patient as well, provided the patient is in a condition to re-use the information constructively.

In addition, the new technology should support the patient with standard patient information about how to cope with his or her specific health situation. This should include information about mental challenges; symptoms that could give her indications for good or for worse; and general knowledge about how to live in a "Wait and See" setting. Furthermore, information about heart transplantation trajectory should be exchanged to the patient's PHR, since the patient could be a candidate for heart transplantation sooner than he or she expects. If the option for heart transplantation is discussed during the follow ups, it is probably time to read about the new trajectory and to acquire knowledge about the issue. Other persons are probably dealing with similar issues (either they are in a wait and see situation, or they are assigned the waiting list to heart transplantation). These human resources should be re-used and shared between privileged users, by use of access to social networks targeting these patient groups. E.g. social networks could be used for information exchange about concerns like how to cope with daily life when living with a heart disease, life style issues, diets, experienced symptoms, treatment, and reflexions on living with a life threatening condition.

4.2.3.6 Needs assessment

A12: Patient returns to acute post-surgery control/consultation

The patient returns for an unscheduled post surgery control shortly after being an out-patient in the regional hospital. It appears that the experienced symptoms were not uncommon, and related to the prior open surgery in which surgeons bend the chest bones back heavily to access the heart organ. Information about how strong this pain could be, and how diffuse the pain could express itself, was left out in the discharge conversation before leaving the regional hospital. New technology should include standard patient information about symptoms and problems that appear after open-heart surgery. The out-patients should be able to access contact information, like a direct telephone number to the thoracic surgery department, or use online communication to discuss problems and support decision making about when to return to for post surgery consultations.

The patient should also have access to social networks to talk to other outpatients that have gone through similar patient trajectories.

4.2.3.7 Knowledge, meaning and quality assurance

A6: *Patient asks for information about a specific test procedure*

A14: Patient asks healthcare providers about what they are doing while they are doing it

A15: Patient gets knowledge about healthcare providers lacking training and experience in using high tech equipment during medical procedures

A16: Patient asks questions during a cardiac catheterization since the healthcare providers doing the procedure seem unfocused

A17: Patient tells the doctors that they have to talk "Norwegian" since he don't understand what they say or write when using "doctor language"

A19: Patient asks the doctor if this treatment is suitable with regard to present drug use (blood diluting drugs)

A22: Patient asks surgeons to translate test results

Activity 14, 15 , 16, 17, 19 and 22 are all addressed to the healthcare providers for quality assurance and to check or make the providers focused on what they are doing while they are doing it. New technology should support patients with standard patient information about

common tests included in assessments and follow-ups related to specific thoracic surgery. Standard patient information could include videos where the test procedure is described and explained in order to provide knowledge and facilitate mental preparedness. In addition, the activities should be supported in the PHR as feedback forms, which could be sent to the intuitions (e.g. the patient could fill out standard forms addressing questions related to the patient experience during the prior hospitalization). These feedback forms could be a neutral feature in which the patient could give feedback about healthcare provides that seem hesitant and uncertain when dealing with new high tech equipment. Then the administration could use the feedback in analysis to improve own healthcare deliveries, and to take concrete actions like scheduling needed training for recently purchased equipment.

As previously mentioned, use of standard patient information could be valuable for patients if written in a patient friendly manner. However, introduction of new technology will not change the way doctors are talking or writing over night. Verbal and written communication is individual skills, and performance varies over doctors.. Use of a medical dictionary integrated with the medical record may be help patients understand medical terms when reading medical record content. Furthermore, patients might transform as patients if being included in own healthcare service by use of new technology. One consequence might be an increased willingness to ask doctors in situations where they do not understand the meaning of the communication. Doctors might also be induced to write the medical record content in a more patient friendly way if they know that the patients are regular readers.

4.3 Interview #2: Trajectory mapping

The participants recognized the individual thoracic surgery trajectory, both with regard to its main phases and its sub phases. They also recalled that they had traversed the trajectory in a manner similar to the one illustrated in the flow chart (see figure 20 & 21 for details). They have made entries to the trajectory from their home residence, and by further referral to local hospital from their regular GP based on the GP assessment during consultation. The advanced medical assessment, ahead of the cardiac evaluation meeting before acceptance or rejection of surgery, was performed at the local and regional hospital for both participants. They tell that they did the ultrasound and ECG examination at the local hospital and the Angiography at the regional hospital. However, they needed to make some small adjustment with regard to their individual "care" flow. E.g. participant A says that she was looping the assessment phase twice before she got acceptance for the aortic valve replacement. Participant B got acceptance for aortic valve replacement during the angiography, or at least the surgeon who did the examination stated that participant B had to be scheduled for an aortic valve replacement. None of the participants got the set surgery time by letter. Participant A received the scheduled surgery time by phone, while (as mention above) participant B received the scheduled surgery time verbally in a face-to-face meeting. None of the participant recalled the standard brochure for heart patients or the patient own report schema, as I showed them these artefacts during interviews. I was provided with this information material from the patient coordinator to the thoracic surgery department. They were also given additional brochures. Participant A did not remember at which phase she got this information. In her recollection it might have been after the surgery. Participant B says that he got a standard brochure about heart patients before surgery. But the brochure was given to him while staying at the local hospital and the included information diverged from the information and experiences he had at the regional hospital. Among other things, he recalls that the brochure stated that all other efforts like diet's, weight reduction and exercise had to be tried before the patient could be considered for surgery. He found this information rather strange, since he experienced being scheduled for thoracic surgery from one day to another.

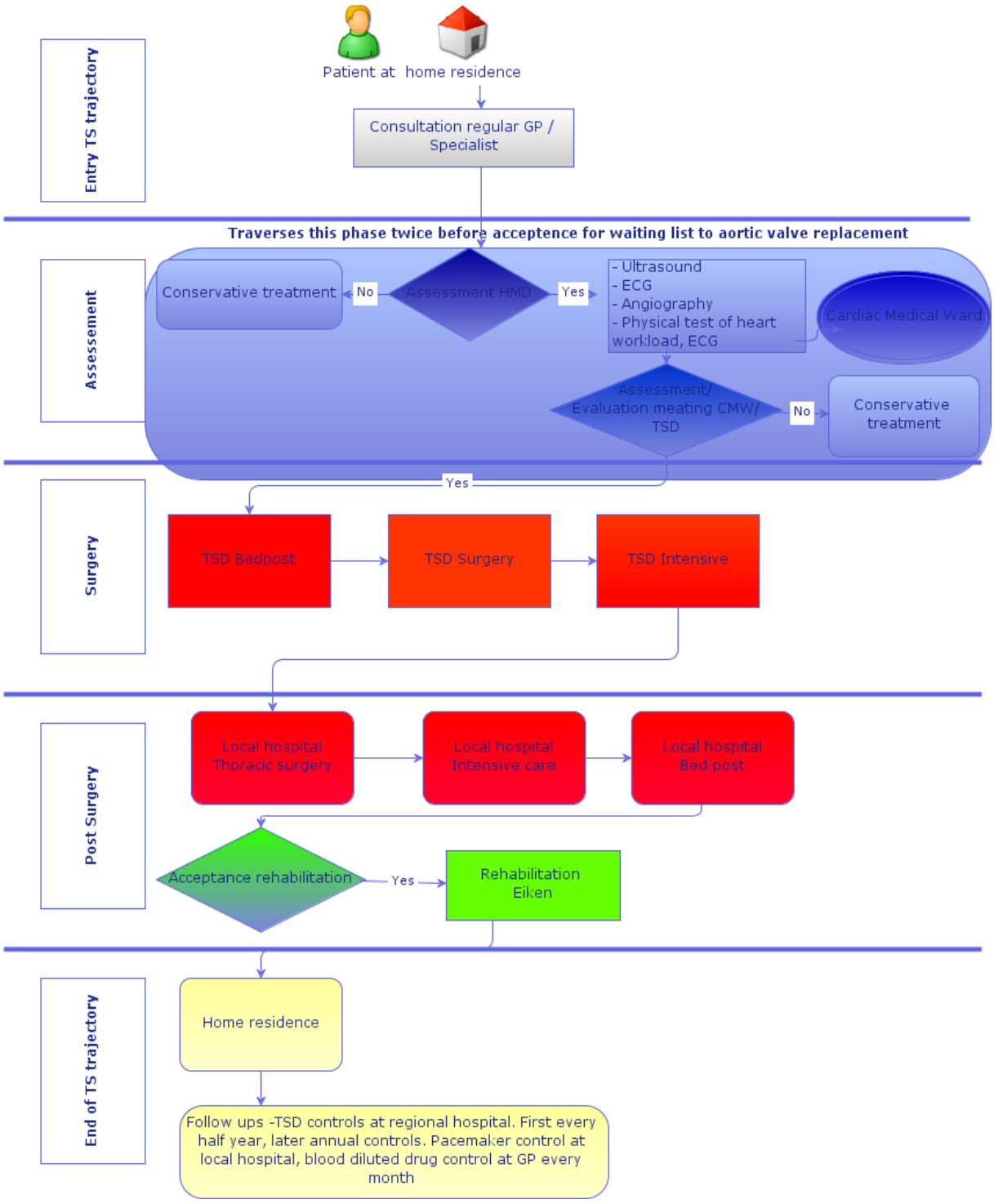


Figure 20: Participant A's own sketch of the thoracic surgery trajectory

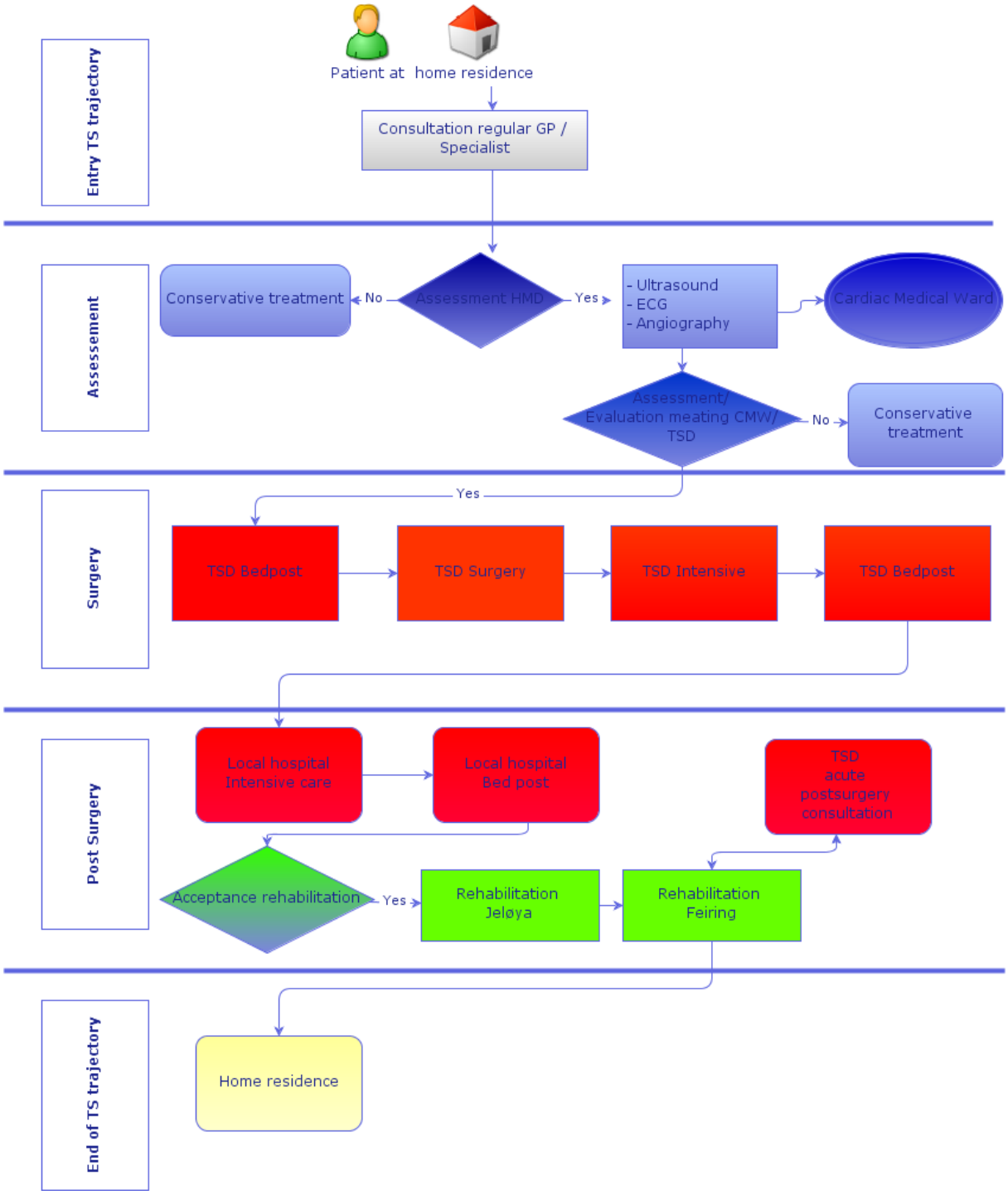


Figure 21: Participant B's own sketch of the thoracic surgery trajectory

The information given to the participants from the local hospital did not coincide with the information given from the regional hospital. It seems like the brochure given to participant B was addressing patients up for conservative treatment. Participant B says that providing diverging information should be unnecessary, and pointed out that it made him confused. He also experienced that the local hospital lacked knowledge about the upcoming thoracic surgery in the regional hospital. When he started gathering information about aortic valve replacements, and alternative valve tissues, the local doctors' response was that "you ask too many questions". . Furthermore, the nurse at the regional hospital that received his calls for information about aortic valve tissue told him that "the surgery is voluntary and you are free to call it off if it is troublesome for you. I do not have time for these phone calls". However, he emphasizes that his questions rarely were met with such a negative attitude. End of story is that participant B had to call the regional surgeon twice, and that he did not met the person with knowledge that he sought before the face-to-face meeting with the surgeon 30 minutes before scheduled thoracic surgery time. The participant did not find this to be an ideal information process but he thinks that the information gap might have been a result of the emergency surgery.

Participant B recognized the surgery phase as illustrated in the standard thoracic trajectory, while participant A did not remember her course during the surgery phase. Participant A did not have to take a stance with respect to the choice of aortic valve tissue, since candidates in her age are assigned for mechanical tissue with few exception (the main exception being cases where the candidates are intolerant to blood dilution treatment). However, she had an unsuccessful surgery, and ended up in an acute condition after the surgery. This complicated her trajectory. She stayed monitored for several days, both in a single-person monitoring room, and in a multi-person surveillance room. Her condition after the surgery was poor. Therefore, she is not able to reconstruct in detail how the days after surgery went by at the regional hospital, or how she traversed the medical posts after thoracic surgery. She has been told that she spent a couple of days in a single-person room while being fully monitored, since her heart rhythm was irregular (too long pauses between heart beats), but she does not remember if this monitoring happened at the intensive care unit or in a bed post. None of the participants were able to recall the number of days they had stayed at the regional hospital, but they both remembered the transfer from the regional hospital to the local hospital they move into the after the surgery phase.

Participant A was transferred to the local hospital in airborne ambulance. Her condition worsened during the transfer and she had to go through an emergency surgery when she arrived at the local hospital. The reason being that her irregular heart rhythm made her pass away several times, and that the local hospital opted for an internal pacemaker. She thinks she stayed at the local hospital for at least two months. In a similar vein, participant B says that he under intensive care for a protracted time period in the local hospital, as he also ran into troubles with the heart rhythm. He therefore had to keep his external pacemaker for a longer time period than is usual after this type of surgery. He also said that he was asked - or almost persuaded - to opt for an internal pacemaker. Still, he was postponed that decision, as he was reluctant to have an internal pacemaker implanted. He told the healthcare providers that they should wait and see, and over time his heart rhythm stabilized itself. Thus, his need for an internal pacemaker was rejected. He tells that he still has issues with high blood pressure, and that he is currently, as previously, constrained by short breath and exhaustion during activities. However, he also experience good days in between, when he is able to perform activities normally.

After local hospital stay, both participants went to rehabilitation clinics where they stayed for several months. They were very grateful for these opportunities, given their reduced health condition after the surgery. They stayed at different types of places and had different experiences. Participant A stayed at a clinic targeting hips and bone injuries. This clinic did not have heart training or other activities targeting heart patients. Participant B stayed at a heart clinic and got extensive heart training that that included lots of information and lecturing about how to cope with being a heart patient. In particular, the heart training program focused on life style change, like recommended diets and physical exercises adapted for heart patients.

As the participants returned to their homes, they entered the follow up phase. Participant A that received surgery in 2005, has been in several annual follow-ups at the regional hospital. In addition, she has had monthly follow ups at her GP, adjusting her dosage of the blood diluting drug (Warfarin). Participant B had surgery in December 2009. He had not received information about scheduled annual follow-ups. He said he still was feeling pain in his chest area and was planning to call his regular GP about it, since the pain was bugging him. While discussing his trajectory, the annual follow up at the regional hospital was a topic, since the time for it was almost due. He was shown the standard brochure about heart surgery (which he had not seen before) from the regional hospital. This brochure contains information about

aortic valve replacement patients, and says that such patients are called in for annual consultations at the thoracic policlinic. The participant said that he would call them straight away to check whether they have scheduled a time for him.

4.3.1 Interview #2: Activities mapped in trajectories

The participants evaluated the identified activities that were mapped into separate steps in the trajectory's different phases. Participant A had only one adjustment to make after quality checking the mapped activities (see figure 22), and that was that her only alternative in future treatment was heart transplantation.

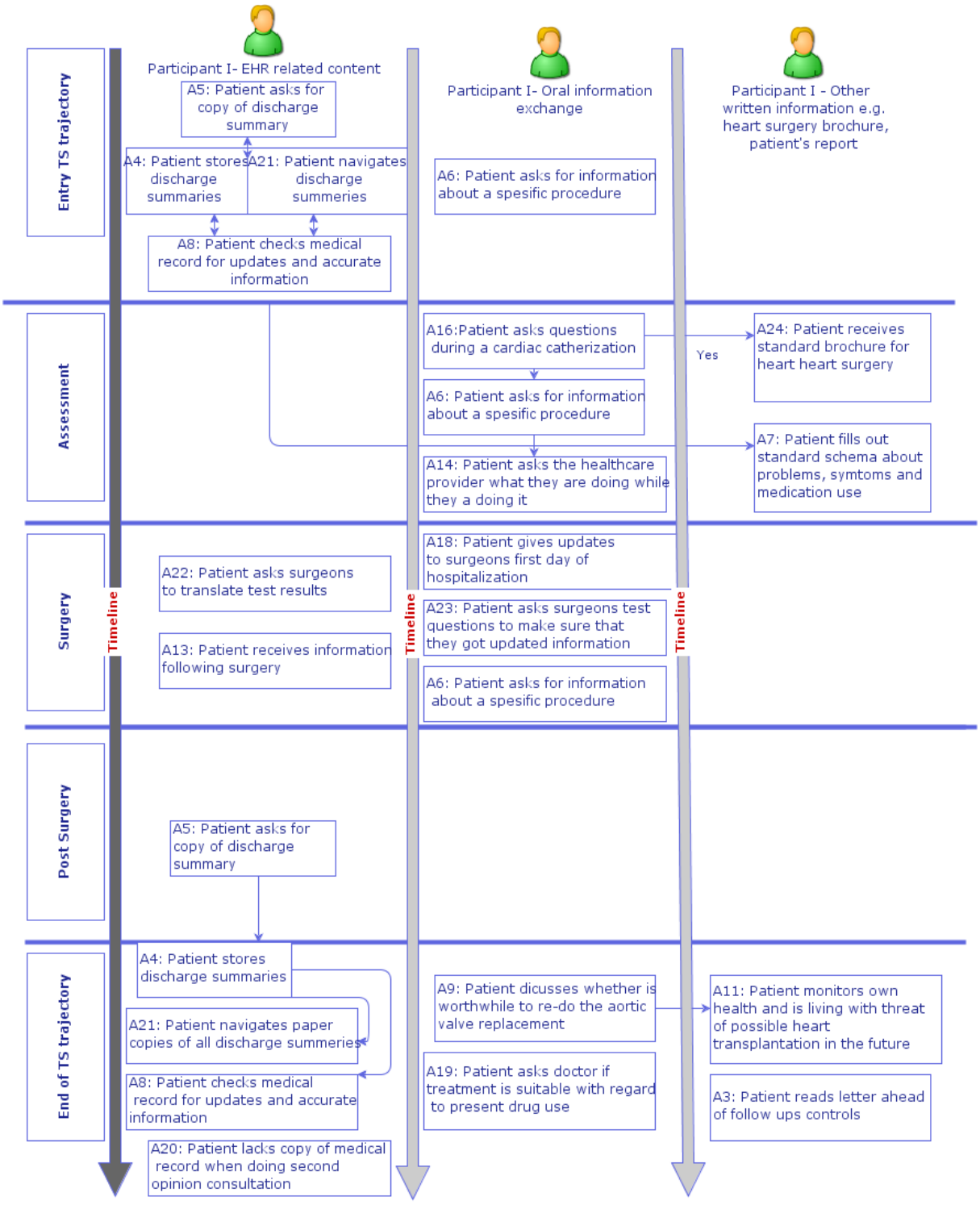


Figure 22: Overview of activities done during thoracic surgery process for participant A.

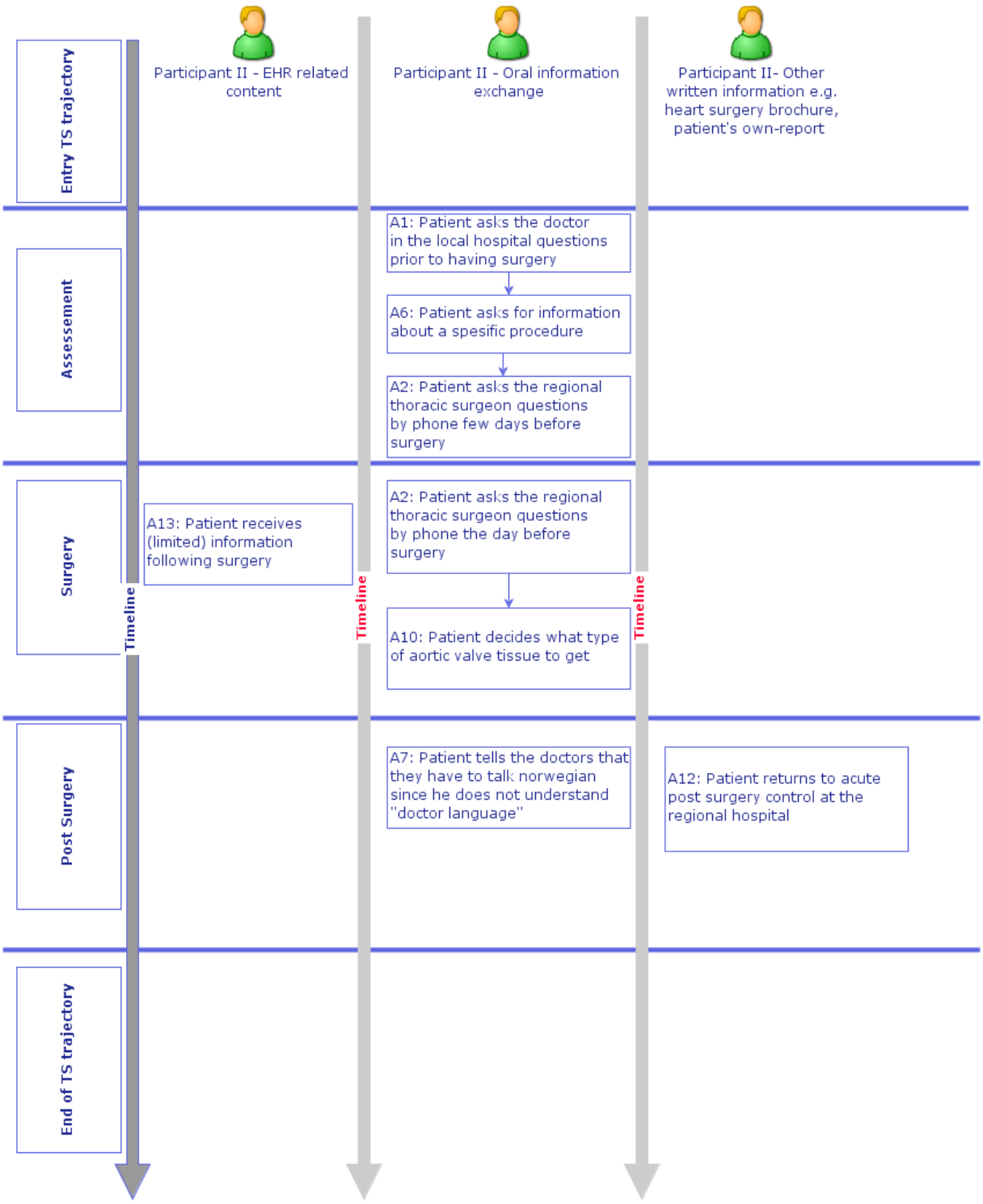


Figure 23: Overview of activities done during thoracic surgery process for participant B.

In addition she emphasized the importance of adding information about new trajectories. In her case this would be targeting information related to heart failure and heart transplantation. In the thesis, her initial entry in a new trajectory is considered to be in the grey zone between the follow-up and assessment phases. During her follow-ups the doctors examined her with a special eye to future treatments and enrolment in a heart transplantation program. Thus, the examination could be considered as assessment as well as a follow-up.

Participant B made some adjustment to the mapped activities (see figure 23). First of all he requested more detailed information following surgery, since the information given at the regional hospital was rather poor. He remembers a surgeon that came to him shortly after he awakened in the intensive care and informed him that the surgery had been successful and that he now had a big pig valve inside his heart. That was all; no further information about the surgery procedure was given to him. The participant says that he would really care for more information about what the doctors saw or experienced during surgery, if something came up, for instance if they tried to fix his natural aortic valve manually. Secondly, he stated that he did not ask the local healthcare providers questions about the high tech equipment during his stay; he only recognized that on several occasions the healthcare providers were struggling while using the equipment. Therefore he likes to remove this activity from the overview.

The regional hospital's standard patient brochure on heart surgery was not available for this participant. He says that he might have been given the brochure at some point in time during his stay at the regional hospital, but that he does not remember the brochure as I show it to him during the interview. However, he did get access to several brochures at the local hospital. As mentioned above, these did not match the information or events at the regional hospital. Thus, the diverging information made him confused and insecure about which information to trust.

While talking about activity 2 (which for him is related to calling the surgeon the day before surgery) he adjusted the action made by adding information that I did not capture during our first interview. The participant says that he was calling the regional hospital's surgeon from his home already during the assessment phase. He had some days at home between assessment and scheduled surgery, and started thinking about some practical issues for the upcoming event. In his first conversation with the surgeon, they agreed to talk further about the decision as soon as he arrived in the hospital. But as he came to the regional hospital bedpost Sunday evening, the surgeon was off duty so their agreed meeting had to be called off. Thus, he was

forced to call the surgeon again - as he still needed to address several questions before making his final decision. He says that as he got information from the surgeon the first time, he started to generate new questions based on his new information. Activity 2 is therefore mapped in both the assessment and in surgery phases. The sentence closure is change to "a few days before surgery" when the activity is mapped to the assessment phase, in contrast to the surgery phase where the original sentence is kept as "the day before surgery".

Participant B comments that he has not received a follow up letter about annual post surgery consultations. He had surgery the 8th December 2009, so he soon is due for a follow up consultation. He stated that he stills feels a lot of pain in his chest area, and while talking about the trajectory he says that he has to call the rehabilitation clinic (Feiring) or his GP to check if he needs to be concerned. He is rather surprised to learn about annual follow-ups. He says that he was in for a three month control at the regional hospital, as he had an acute pain situation a short time after surgery. As we read the standard patient brochure about heart surgery together (which he had never seen before), he learns that aortic valve replacement patients gets an annual control at the policlinic. His reaction is that he will call the policlinic straight away to check if they have scheduled a time for him, since he has experienced problems and symptoms that constrains his activities.

Participant B has performed less health information activities during this thoracic surgery trajectory than participant A (see figure 22 and figure 23). His activities are all based on exchange of verbal information, while participant A uses both verbal and written information sources. This difference may result from the fact that participant A has a lifelong experience in being a patient (as she was born with a heart failure). She knows how to interact and collaborate with her healthcare providers. Participant A take great interest in reading and managing own medical record at home. This is in contrast to participant B, who has shown no activity with respect to use of his medical record as a tool. Participants B say that the written content in the medical record is unreadable to him, and that if he needs a copy he will goes to his GP and get it. The main difference between the two participants is their behaviour with regard to their intentionality of asking questions during examination, and their use of the medical record. They have both indicated individual activities giving information gaps in outcomes that are troublesome during decision making. When studying participant A's activities, she seems active and experienced as a patient, asking critical questions to her healthcare provider during regular interaction. Participant B's actions reveal that he does not

give up his search for pieces of information he considers to be necessary, e.g. as he repeatedly made phone calls the surgeon in order to get information about aortic valve tissue.

4.4 Participatory design

4.4.1 Timeline

The experimental design process revealed that the participants' had different informational needs with regard to the monitoring of subjects that had concerns about the outcome of their aortic valve replacement, and their current health status.

Participant A expresses no interest in displays of timeline views showing heart rhythm or ECG, since her pacemaker supports her heart in beating regularly. Her concern was rather related to the mechanical aortic valve that requires daily intake of the blood diluting drug Warfarin. The dosage of Warfarin has to be adjusted based on a test called PT-INR (Prothrombin Time and International Normalized Ratio). She is undergoing this test on a monthly basis in her GP's lab. Based on an analysis of the PT–INR results, the participant together with her GP decides whether the current dosage can be upheld or needs to be adjusted. Travelling to the city on a monthly basis to take the test is time consuming to her. She says that "her daily life would be a lot easier to her" if she could do the test at home, and make the decision with regard to dosage online (in collaboration with her GP). Therefore, she chooses to design a timeline view for the PT-INR test, as well as one for the blood diluting drug dosage. Furthermore, she thinks that home test of SPO_2 level during daily activities and timeline view of these results over time, would be a helpful object to monitor. The reason being that some days she feel tired and needs to rest, while other days her activities do not affect her that much. By monitoring the uptake of oxygen in her blood during regular activity, she might get an indicator of her heart and lung function. All monitoring and blood test results done at home would have to be transferred to the GPs office, or to her heart specialist in the local hospital. Her designed timelines is illustrated in figure 21.

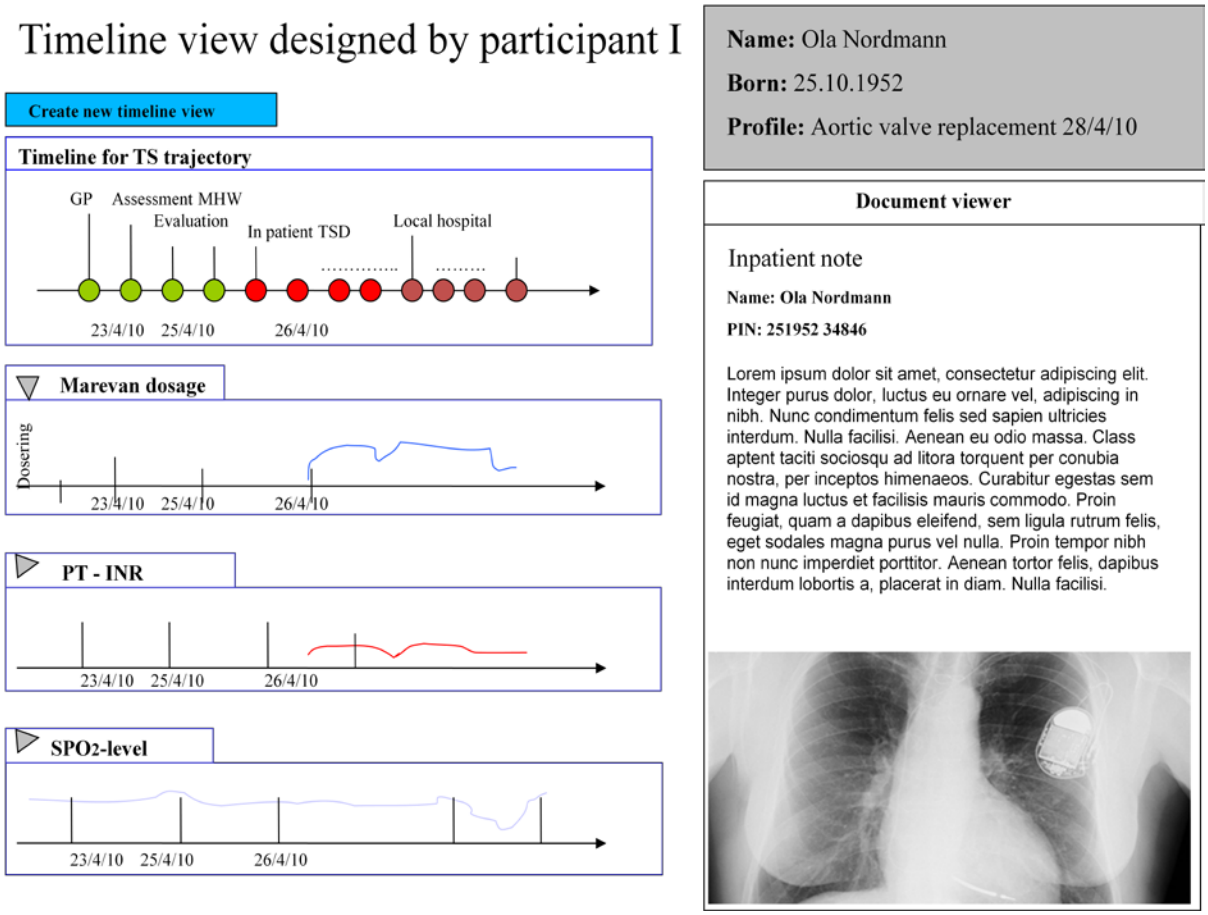


Figure 24: Overview of participant A experimental design outcome with regard to user interface displaying relevant information of concern.

In addition to this she would like to view textual information associated with the link in the screen shot illustrated in the right of figure 24. She also finds views of pictures, like x-rays, to be of great value. The x-rays do not necessarily have to be displayed together with the translation of them, but she finds both information sources useful. With regard to her health condition and the examinations undergone, she says that few x-rays are actually included in her medical record. As she has greatly worries about her daughter's well being and healthcare; she views the x-rays pictures as potentially extremely helpful. Her daughter has frequently had bone injures, and x-rays in a time perspective for comparison would support participant A greatly when following up her daughter in the meetings with healthcare providers.

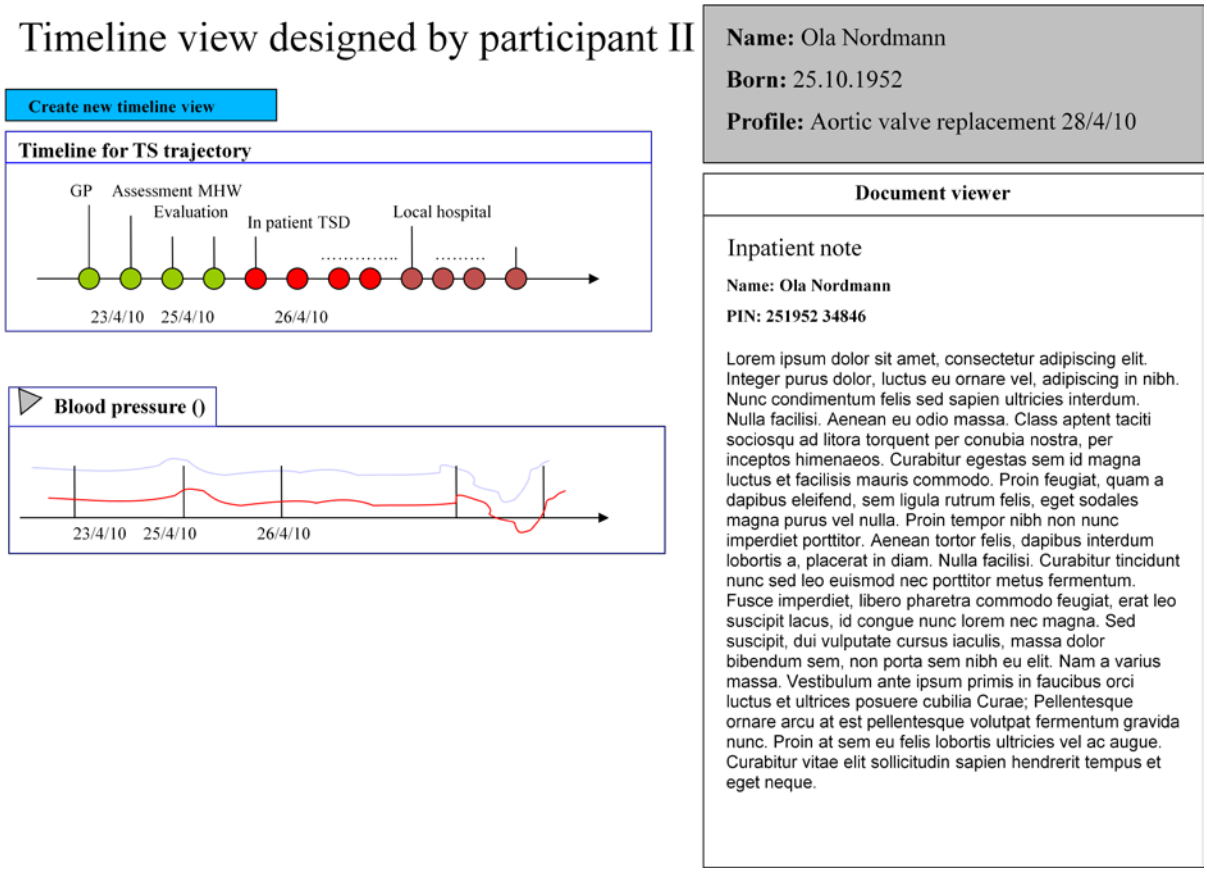


Figure 25: Overview of participant B experimental design outcome with regard to user interface displaying relevant information of concern

Participant B says that his main concern is high blood pressure: He would therefore prefer to measure the blood pressure at home and monitors it by a timeline view (see figure 25). He states that he takes some medications, but that he does not find it useful to monitor any of them specifically. He prefers a simple design and view, and therefore finds it convenient to limit the timeline view to information associated with the different trajectory phases, together with the blood pressure view over time.

4.4.2 Content to be viewed

The participants were invited to design information sources by adding labelled notes to the A3 printout of the timeline view. Added features should be accessible when clicking on the links to the different phase in the thoracic surgery trajectory (see illustration in figure 26). Both participants had a mutual interest in accessing and viewing information both from the medical record and from standard patient information sources associated with each phase in the trajectory. However, since none of the participants found the medical record content useful by

itself, the record design to PHR information content is referred to as “health record” information.

Participant A stated that in addition to the medical record and the standard patient information belonging to the each phase within the timeline, she would find it really useful to have the patient’s legal rights included as well. Further she says the patient legal rights could be included in other features within the PHR as well, e.g. in the calendar view, or as information received by mail as a personal remainder. The importance of a legal rights notice is that she has experienced not using important patient rights such as physiotherapy training because she did not realize that she had this right automatically after the first phone call from the physiotherapist – and that she had a right to such services over the next half year.

Participant B acknowledged and emphasized the importance of getting extended and adjusted standard patient information during the initial stage of the trajectory. He says that he personally experienced a great deal of stress, as he had to gather the information he needed for decision making by himself, during the assessment phase. To him, access to adjusted and accurate standard patient information would have been extremely helpful as support. However, he says that for him the standard patient information could never replace the face to face meetings between the patient and provider.

Participant B was also interested in getting reminders about patients’ rights, including right to physical exercise with professional surveillance. He said he was offered the opportunity to exercise under the guidance of the physiotherapist, but decided to exercise in a private health centre called SATS instead. He says that he experienced pain during exercise, and stopped training. He speculates that if he had gotten regular reminders from the physiotherapist prior to his scheduled exercise appointments, he might have continued exercising since he would have been more comfortable in putting pressure on himself.

Name: Ola Nordmann

Born: 25.10.1952

User profile: Aortic valve replacement surgery 28/4/10

Timeline view

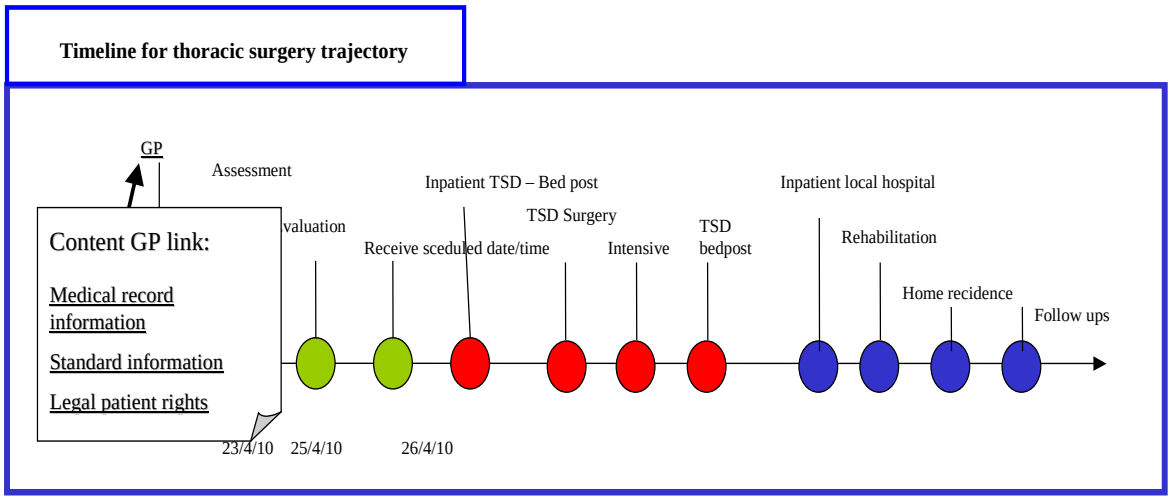


Figure 26: Participant A and B's contribution with regard to information design that should be accessible at each phase in the thoracic surgery trajectory.

Participant A says that even if she got access to her medical record file as a whole, she would never find an explanation of why her aortic valve surgery failed after surgery. She says that during the initial surgery the surgeons have guidelines to try to rebuild the aortic valve as it is, before resorting to the aortic valve replacement. She thinks that something happened during this trial. Since the medical record does not report anything about rebuilding the aortic valve, she will not – in her opinion – get access to the information she is searching for by accessing the medical record. She recommends that standard patient information should be set according to clinical guidelines, and that the doctor notes should be structured as a response to these guidelines. By organizing it in such a way it would be possible to follow and understand the decision making of the surgeon(s); as it would be documented step by step within the surgery note. It would also facilitate an understanding of the direction taken in the trajectory.

As these two participants convey, several aspects related to their differences in outcome of surgery and aortic valve replacement tissue influences their individual information needs. For example, participant A, who has a pacemaker, says that information about heart rhythm or ECG is not that relevant to her. To meet the needs of these two participants, it is acknowledged that objects displayed in the timeline view should be optional, and designed by each user of the PHR. Nonetheless, available options should be limited to central aspect of being a heart patient. In my view having a pacemaker is not uncommon for heart patients, and participant A's information needs generated by being a pacemaker user is probably shared with several potential users of PHR.

Since this study was carried out within a time span of a year, and was under constraints of time and project funding, meetings with the participants were only conducted twice. The participants will be invited to access the web-based prototype in the end, in order to view the results of the design project. This is done to assure them that their contributions have been valuable, and to show them that their inputs have been indispensable in developing the prototype.

4.5 Prototype design

The proposed prototype PHR has domain www.thoraxpasient.com, and includes partial prototype design since the health information overview application is not implemented within the website (See figure 27). The timeline is developed by used of Infragistics's Windows® Presentation Foundation (WPF) timeline control (trial version software) and Visual Studio 2010. The front page of Thoraxpasient.com contains a primary menu in the header and a secondary menu in left sidebar. The primary menu contains menu items labelled *About Thoraxpasient, Thoracic surgery, Thoracic Surgery trajectory, Mailbox, Resources and Frequent Asked Questions*. The right sidebar contains search functionality (including advanced search), calendar view, latest 5 discussions and a patient poll. The website's content is written in Norwegian language, but since it is developed by use of the open source software Drupal, some modules have functionalities that include English text. The background picture in the front page's header is an illustration of the "one door in" principle, in the meaning of patients' accessing own patient trajectories' information, including medical records and valuable standard patient information, regardless of its originators like EHR systems, healthcare provider or healthcare institutions.

Figure 27: Overview of the front page thoraxpasient.com

4.5.1 **Timeline**

Further in the prototype design chapter, I will focus on the information visualization of health information. Based on the previous analysis and participatory design, I have developed a timeline prototype for the thoracic surgery trajectory. The timeline application is separated from the web site in this prototype version. The overview displays information visualization of health information that participants found useful to access for support during the thoracic surgery trajectory. The page layout consists of four rows (welcome message, main timeline, timeline selection list and optional timeline) and two columns (first column consist the rows and second column consist a document viewer). The main timeline (timeline on top), includes the patient's events / sub phases during the thoracic surgery trajectory.

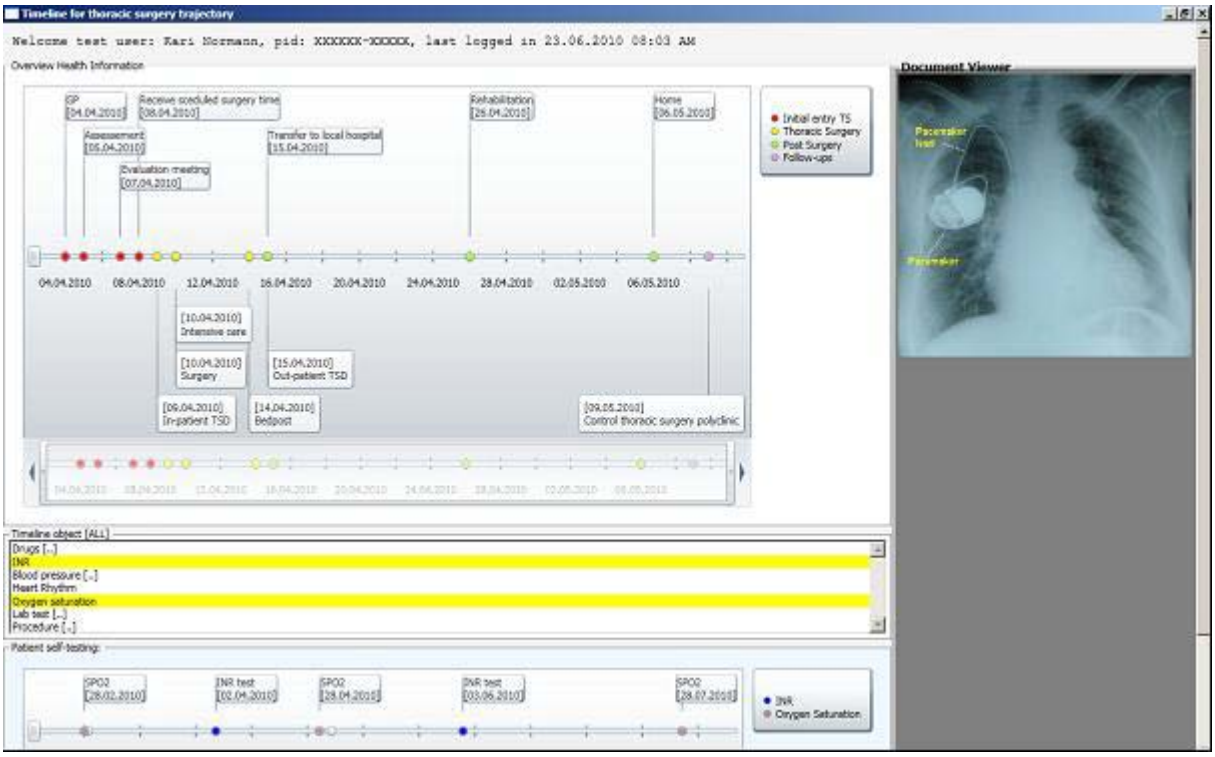


Figure 28: Overview of health information visualization

The events / sub phases are highlighted by colored items that are plotted in the timeline in relation to their belonging main phase including *initial entry thoracic surgery* (red), *thoracic surgery* (yellow), *post surgery* (green) and *follow-ups* (purple) (see figure 28 and 29). The bottom scroll bar makes it possible to both expand and zoom the date range for ease of navigation. The events are connected to the timeline by date, and by clicking on the event's line item you find details about the event. In the right column (figure 28), a dedicated area is created for document views. The area is small and requires that the display can be scaled in size.

4.5.2 **Content to be viewed**

All events contain standard patient information and legal patient right information, but the medical record content varies from event to event. The reason for this being is that each event includes content gathered from the medical record, which is associated to the respective sub phase.

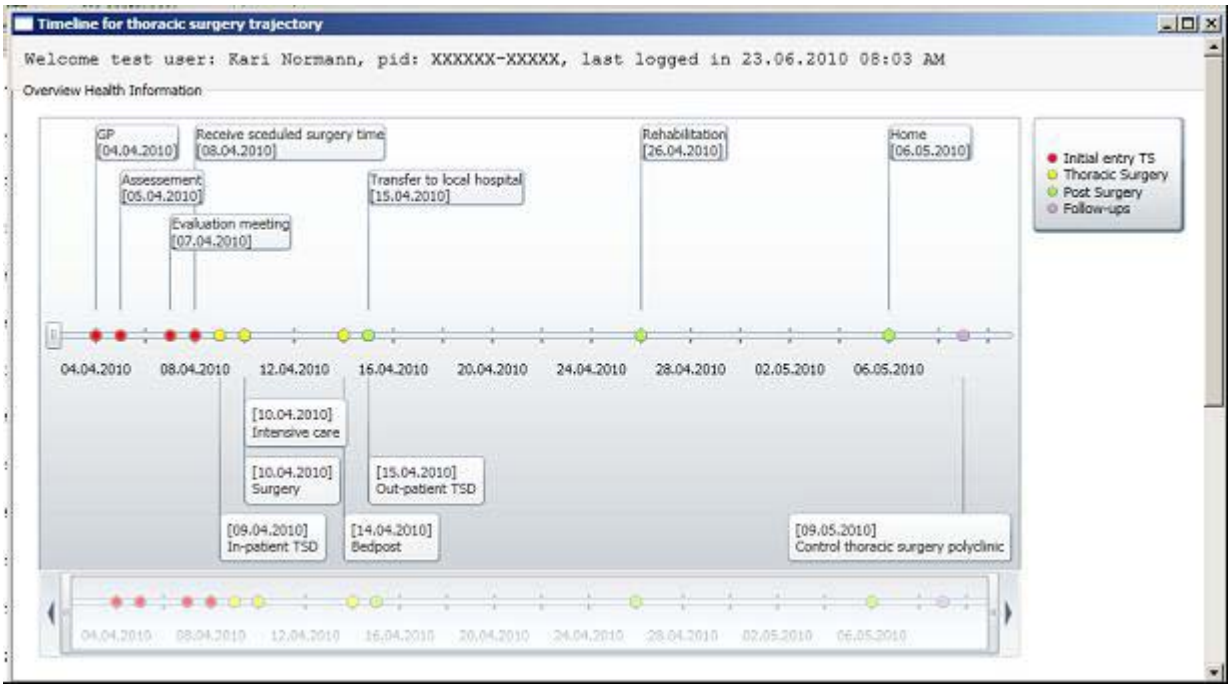


Figure 29: Overview thoracic surgery trajectory timeline

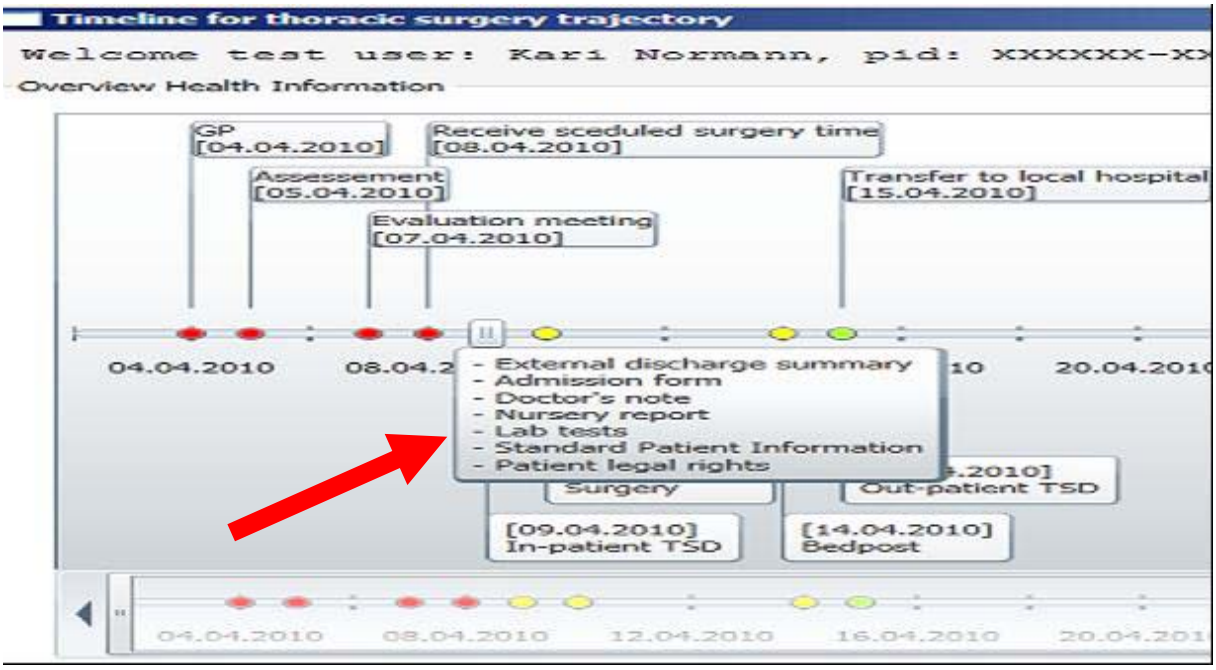


Figure 30: Overview health information content within event "box"

E.g. the event labelled *In-patient* contains aggregated medical record content including external discharge summary (from GP and / or local hospital), admission form, doctor's note, nursery report and lab tests. The In-patient event could probably be associated with other parts of the record content, but the chosen files are suggestions to illustrate how the medical record content could be presented to improve navigation and information access.

In addition to the main timeline including overview of relevant health information, the participants want to make own timelines based on individual need for health surveillance. The timeline objects list includes common objects that are useful for heart patients to observe like heart and lung function monitoring (blood pressure, heart rhythm, and oxygen saturation), drugs, INR and other medical procedure / examination.

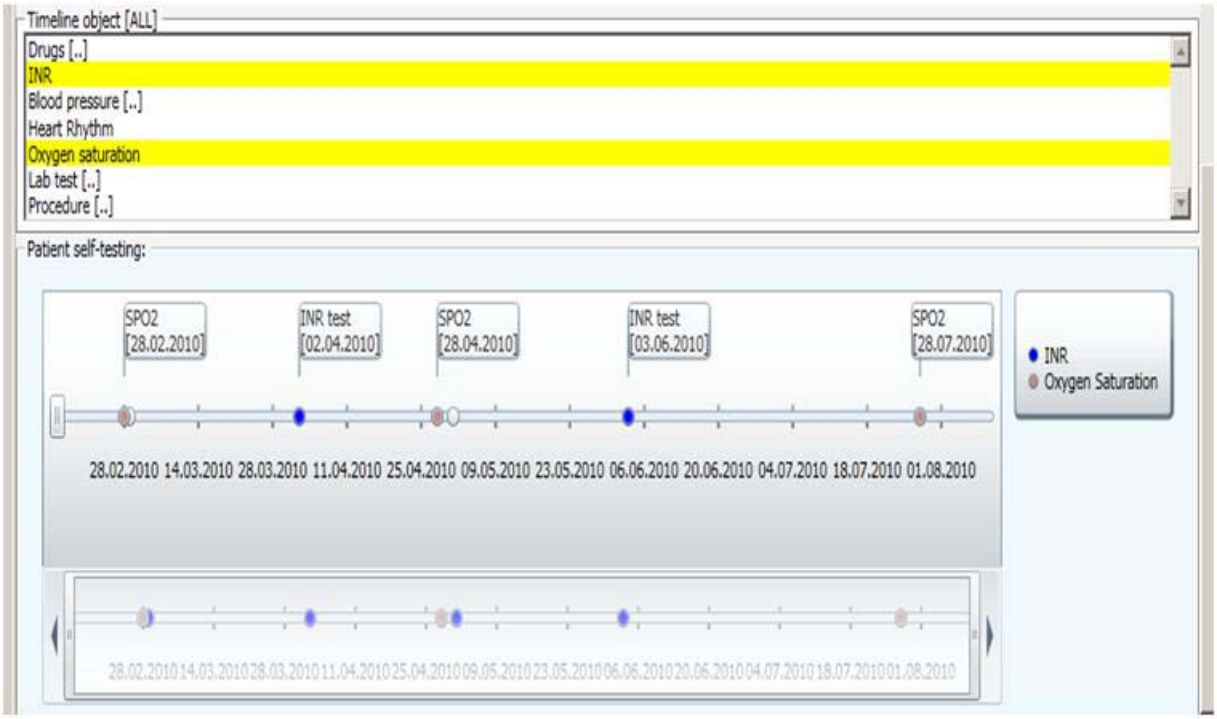


Figure 31: Overview patient's own timeline of interest

The screenshot shows an illustration of the selection-based timeline, whereas INR and Oxygen saturations are selected as objects to display within the timeline. By giving patients options to design own timeline views, they have a tool to monitor individual health interest and to better take care of own health.

5 SYSTEM REQUIREMENTS

5.1 Information system specification

A system requirement is that the developed prototype for the future information system to thoracic surgery patient will have to correspond with the patient health record (PHR) technology. Thus, the participants are presented with possible solutions associated with PHR technology, and use those solutions as a framework for further development of the final prototype. The information content and how the content is displayed are specifications set by the participants through interviews and experimental design. During the participatory design process their patient activities, user needs and behaviour are identified and used actively in further design. The core information within the system are standard patient information and medical record contents, and information of special concern gathered from these records are aggregated. The information system should have features that support the patients in their reading of the medical content. The information should be structured and presented in ways that are understandable for the users. It is a requirement that the prototype illustrates how patients can get access to relevant health information that can support them in different phases of their thoracic surgery trajectory. Which health information that is relevant to create accurate and timely knowledge in each phase, is a system specification that is set by the participants. A system requirement is that the information should be related to the thoracic surgery process only, and therefore should be associated with the informational needs of the participants from the initial entry of the trajectory and until the end of it. The patient's information system is a part of the healthcare services delivered by the Oslo university hospital, and the goal of the new technology is to support the patients during their interaction with healthcare providers. Thereby new technology might improve the hospital's healthcare services.

5.1.1 Layout system specification

It is a system requirement that the visual appearance of the prototype should be associated (as well as possible) with the visual profile and layout used in similar information systems by the Oslo university hospital (http://www.oslo-universitetssykehus.no). The information system is a (trial) version and a tool for patients who are provided with healthcare services from Oslo university hospital. Thus, the new technology should reflect the fact that it belongs to this hospital by applying the requisite layout, including selected colours, textual layout and logo. The design layout of the hospital's logo is developed by use of two main colours; blue (HEX

#00 33 8D) and warm gray (HEX #9A 99 6E). The hospital design team bases their choice on the following reasoning: "*The cross has a warm gray colour in contrast to the colder bluish hues of the circle. Together they create well-balanced colours and at the same peculiar expression, which expresses the seriousness and care.*"

In addition the hospital's design profile includes ten supporting colours that have been selected as they are considered to be "*bright colours to reflect a positive and welcoming organization*". The hospital's design team also want their layout profile to be "*distinctive and recognizable"*. The selected additional colours are harmonizing and complementing the colours in the hospital's logo. The ten supporting colours appears in shades such as: red (HEX #C6 0C 30), orange HEX #FF 79 00, warm yellow HEX #FD C8 2F, green HEX #3F 9C 35, blue/green HEX #00 73 63, clear blue HEX #00 A9 224, blue HEX #00 65 BD, purple HEX #7D 00 63, and gray HEX #82 84 7A.

The hospital uses Calibri and Cambria as main fonts in their production and layout of information materials. The hospital's design group has evaluated these fonts to be working for printed materials as well as screen-based applications. However, they have chosen Verdana as the main font included in the hospital's websites. These three fonts are all system fonts that are supported in most web browsers and software, included in PCs.

A graphical remedy that Oslo University hospital uses in their websites is pictures of humans. The extended use of pictures is a conscious choice that emphasizes to their audience that the hospital keeps the human in focus, and that humans are the main attention. The pictures display light appearance and close-ups of humans that illustrate positive human interactions. The pictures have machinery and technology kept in the background. This graphical approach is used to on the institution's website (and other hospital information materials) to produce a "personal touch", in opposition to the "huge" and "impersonal" institution many patients are likely to associate the hospital with.

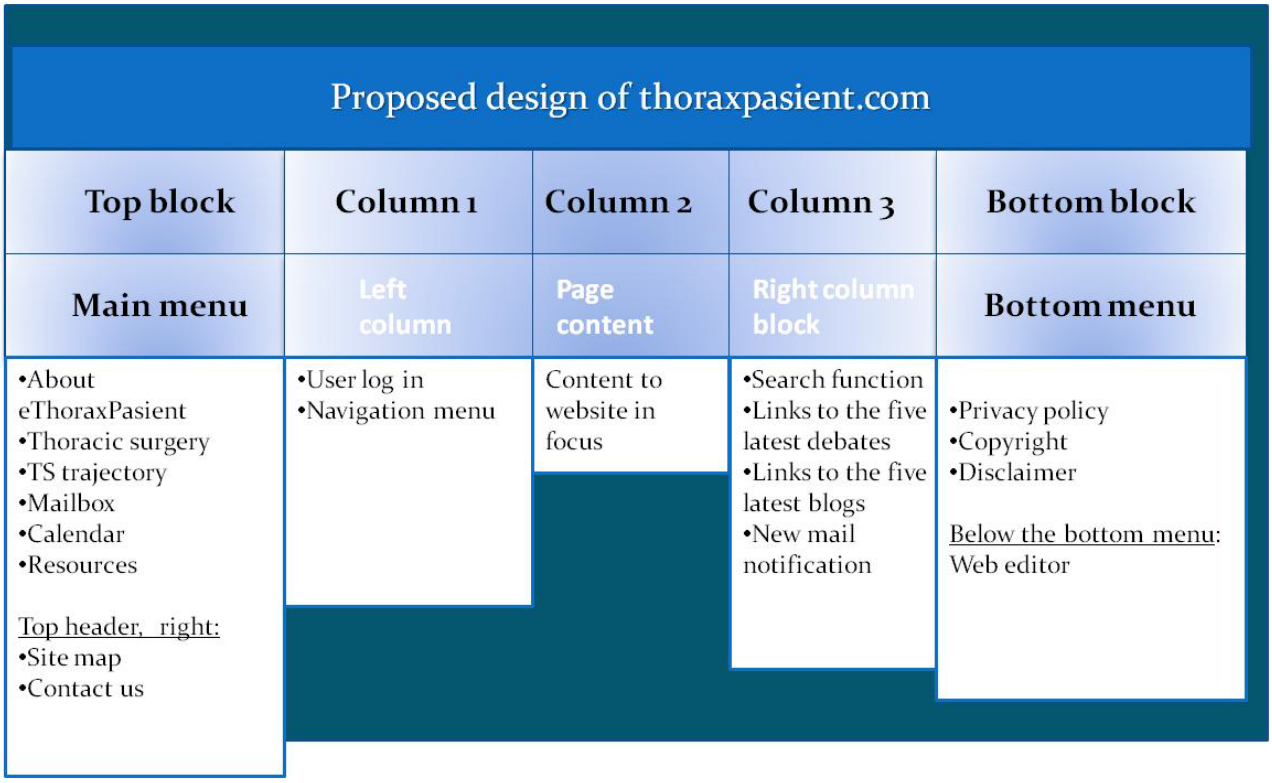
The picture used in the header of the website to the PHR prototype, which illustrates an open door and white background, is related to access to information and the hospital environment. The mirroring effect is used to achieve a feeling that that patients and healthcare providers have a common entry to the patient information; since they both are sources and users to the generated information within the information system. The open door is a symbol to the patient

– it signifies that “you may access your medical information in a similar manner to the healthcare providers”.

5.1.2 Design of Information system

Design of the information system named thoraxpatient.com displays a horizontal primary menu below in the header area. The primary menu contains six menu items (see the content map below for details). In the left column block one finds the log in, navigation menu and calendar. In the right column one can locate the search function at the top, the latest added comments in the middle, and links to the latest social networks debates below. In the bottom menu one finds links to contact information, site map, privacy policy and copyright statement. Below the bottom menu the link to the web editor is included.

Content map to http://www.thoraxpasient.com



The content displayed in the front page of thoraxpatient.com is dedicated to relevant health news added by the web editor. The front page is accessible by any guest that for some or another reason chooses to visit thoraxpatient.com. The news listed as hyperlinks will therefore

be of general characters e.g. related to treatment, lifestyle issues or other heart related information. The vision is that potential thoracic surgery patients already during assessment will get access to the website. Patients that enter the trajectory are either assigned to waiting lists or starts conservative treatment. Patients that receive conservative treatment may also need informational support as they are often motivated to change lifestyle in order to improve their health. To get access to the thoraxpatient.com user profile one has to be approved as a user by the healthcare provider's patient coordinator, or by others working in the administration of the thoracic surgery department. Approved users will get access to the following information and features in this prototype version 1.1:

1. Medical record content (only fake record data during trial)
2. Standard patient information for each phase within the trajectory.
3. Overview of medical record content and standard patient information organized after phases included in the trajectory
4. Private blog that is working as a private diary
5. User profile with option for uploading personal picture
6. Mail box for information exchange with the healthcare provider
7. Social network for patients only that have entered the thoracic surgery trajectory
8. Social network for patients where a healthcare provider answering questions address
9. A frequent asked questions (FAQ) list
10. Calendar for organizing appointments and healthcare services.
11. Web form of the schema for patient own report

The main objective in this version of PHR prototype is the requirement that relevant health information is included, visualized and displayed as a timeline. The timeline view has requirements for ease of use, so the users' interaction with the timeline needs to be kept to a minimum.

5.1.3 Prototype version

PHR prototype is version 1.1.

5.1.4 Test user

Test users of eThoraxPasient may employ the username: ***pasient*** with password ***Pasient123*** for access and testing of the interface to the proposed prototype.

5.1.5 Tool used during development of prototypes

The paper-based prototype is illustrated by MS power point presentations.
The web based prototype is developed by use of Drupal version 6.13, which is an open source content management system that includes My SQL database, CSS, PHP and xhtml programming. The timeline is developed by used of Infragistics's Windows® Presentation Foundation (WPF) timeline control (trial version software) and Visual Studio 2010 , together with use of programming language WPF, including xaml and Silverlight.

5.1.6 Program code of timeline prototype

```
<!—Create a window with class named timeline -->
<Window x:Class="Tidslinje.MainWindow"

<!—Includes necessary libraries -->
xmlns="http://schemas.microsoft.com/winfx/2006/xaml/presentation"
xmlns:x="http://schemas.microsoft.com/winfx/2006/xaml"
xmlns:igtl="http://schemas.infragistics.com/xaml"

<!—Title the application window -->
Title="Timeline for thoracic surgery trajectory">

<ScrollViewer><!—Select ScrollViewer for adding vertical scrollbar to the grid
-->
<Grid Background="WhiteSmoke"><!—Set background color -->

<Grid.RowDefinitions><!—Add four rows to the grid layout -->
   <RowDefinition/>
   <RowDefinition Height="Auto"/>
   <RowDefinition Height="Auto"/>
   <RowDefinition/>
</Grid.RowDefinitions>

<Grid.ColumnDefinitions><!—Add two columns to the grid layout -->
   <ColumnDefinition Width="Auto"/>
   <ColumnDefinition/>
</Grid.ColumnDefinitions>

<!—Styling grid by color and text layout, and add welcome message-->
<Label Grid.Row="0" Grid.Column="0" Background="WhiteSmoke" Foreground="Black"
                 HorizontalContentAlignment="Left" FontSize="14"
FontFamily="Courier New" Padding="10px"> Welcome test user: Kari Normann, pid:
XXXXXX-XXXXX, last logged in 23.06.2010 08:03 AM </Label>


<!—Add a groupbox to organize content in first row and first column-->
```

```
<GroupBox Grid.Row="1" Grid.Column="0" Background="White" Header="Overview
Health Information">

<!—Creating the frame for timeline view including height and width -->
<igtl:XamTimeline x:Name="xamTimeline" Width="900" Height="430" Margin="15">
 <igtl:XamTimeline.Series>

<!-- Add Date Time Entries for the initial entry TS -->
<igtl:DateTimeSeries Title="Initial entry TS" Position="TopOrLeft" Fill="Red">
<igtl:DateTimeSeries.Entries>
<igtl:DateTimeEntry Time="04/04/2010" Title="GP" AllowDrop="True"
 Details= "- Doctor note
           - Referral form
           - Standard Patient Information
           - Patient legal rights" />

<igtl:DateTimeEntry Time="04/05/2010" Title="Assessement"
Details= "- Doctor note local hospital
          - Referral form
          - Doctor note regional hospital
          - ECG diagram
          - Ultrasound image
          - Standard Patient Information
          - Patient legal rights" />

<igtl:DateTimeEntry Time="04/07/2010" Title="Evaluation meeting"
Details= "- Doctor note
          - Referral form
          - Standard Patient Information
          - Patient legal rights" />

<igtl:DateTimeEntry Time="04/08/2010" Title="Receive scheduled surgery time"
Details= "- Letter from hospital
          - Standard Patient Information
          - Patient legal rights" />

</igtl:DateTimeSeries.Entries>
</igtl:DateTimeSeries>


<!-- Add Date Time Entries for the thoracic surgery phase-->
<igtl:DateTimeSeries Title="Thoracic Surgery" Position="BottomOrRight"
Fill="Yellow">
<igtl:DateTimeSeries.Entries>

<igtl:DateTimeEntry Time="04/09/2010" Title="In-patient TSD"
Details="- External discharge summary
         - Admission form
         - Doctor's note
         - Nursery report
         - Lab tests
         - Standard Patient Information
         - Patient legal rights" />

<igtl:DateTimeEntry Time="04/10/2010" Title="Surgery"
Details="- Surgery note
         - Doctor's note
         - Nursery report
         - Lab tests
         - X-rays and monitoring diagrams
         - Standard Patient Information
         - Patient legal rights" />


<igtl:DateTimeEntry Time="04/10/2010" Title="Intensive care"
```

```
Details="- Doctor’s note
         - Monitoring diagram
         - Lab tests
         - Nursery report
         - Standard Patient Information
         - Patient legal rights" />


<igtl:DateTimeEntry Time="04/14/2010" Title="Bedpost"
Details="- Doctor note
         - Nursery report
         - Lab tests
         - Monitoring diagrams
         - Standard Patient Information
         - Patient legal rights" />

<igtl:DateTimeEntry Time="04/15/2010" Title="Out-patient TSD"
Details="- Discharge summary
         - Referral from
         - Standard Patient Information
         - Patient legal rights" />

</igtl:DateTimeSeries.Entries>
</igtl:DateTimeSeries>

<!-- Add Date Time Entries for the post surgery phase-->
<igtl:DateTimeSeries Title="Post Surgery" Position="TopOrLeft"
Fill="GreenYellow">
<igtl:DateTimeSeries.Entries>

<igtl:DateTimeEntry Time="04/15/2010" Title="Transfer to local hospital"
Details="- Admission form
         - Doctor note
         - Lab tests
         - Monitoring diagram
         - Standard Patient Information
         - Patient legal rights" />

<igtl:DateTimeEntry Time="04/26/2010" Title="Rehabilitation"
Details="- Admission form
         - Discharge summary
         - Doctor's note
         - Standard Patient Information
         - Patient legal rights" />

<igtl:DateTimeEntry Time="05/06/2010" Title="Home"
Details="- Discharge summary
         - Standard Patient Information
         - Patient legal rights" />

</igtl:DateTimeSeries.Entries>
</igtl:DateTimeSeries>

<!-- Add Date Time Entries for the follow ups phase -->
<igtl:DateTimeSeries Title="Follow-ups" Position="BottomOrRight" Fill="Plum">
<igtl:DateTimeSeries.Entries>
<igtl:DateTimeEntry Time="05/09/2010" Title="Control thoracic surgery
polyclinic"
Details="- Letter for the secduled control time
         - Doctor's note
         - Standard Patient Information
         - Patient legal rights" />


</igtl:DateTimeSeries.Entries>
```

```
</igtl:DateTimeSeries>
</igtl:XamTimeline.Series>

<!--Set the timeline axis properties to days -->
<igtl:XamTimeline.Axis>
<igtl:DateTimeAxis AutoRange="True" UnitType="Days" Unit="0"/>
</igtl:XamTimeline.Axis>
</igtl:XamTimeline>
</GroupBox>

<!—Add a groupbox to organize content in second row in first column-->
<GroupBox Grid.Row="2" Grid.Column="0" Background="White"  Header="Timeline
object [ALL]">
<!-- Add listbox to organize the available options for timeline objects -->
<ListBox ScrollViewer.VerticalScrollBarVisibility="Visible">
      <ListBoxItem>Drugs [..]</ListBoxItem>
      <ListBoxItem Background="Yellow">INR</ListBoxItem>
      <ListBoxItem>Blood pressure [..]</ListBoxItem>
      <ListBoxItem>Heart Rhythm</ListBoxItem>
      <ListBoxItem Background="Yellow">Oxygen saturation</ListBoxItem>
      <ListBoxItem >Lab test [..]</ListBoxItem>
      <ListBoxItem >Procedure [..]</ListBoxItem>
</ListBox>
</GroupBox>

<!—Add a groupbox to organize content in third row in first column-->
<GroupBox Grid.Row="3" Grid.Column="0" Background="AliceBlue" Header="Patient
self-testing:">

<!—Creating the frame for optional timeline view including height and width -->
<igtl:XamTimeline x:Name="xamTimeline2"  Width="900" Height="210" Margin="15">
<igtl:XamTimeline.Series>

<!-- Date Time Entries INR -->
<igtl:DateTimeSeries Title="INR" Position="TopOrLeft" Fill="Blue">
<igtl:DateTimeSeries.Entries>
<igtl:DateTimeEntry Time="03/01/2010" Title="INR test"
Details="Details Time Entry"/>
<igtl:DateTimeEntry Time="04/02/2010" Title="INR test"
Details="Details Time Entry"/>
<igtl:DateTimeEntry Time="05/01/2010" Title="INR test"
Details="Details Time Entry"/>
<igtl:DateTimeEntry Time="06/03/2010" Title="INR test"
Details="Details Time Entry"/>

</igtl:DateTimeSeries.Entries>
</igtl:DateTimeSeries>

<!-- Date Time Entries SPO2 -->
<igtl:DateTimeSeries Title="Oxygen Saturation" Position="TopOrLeft"
Fill="RosyBrown">
<igtl:DateTimeSeries.Entries>
<igtl:DateTimeEntry Time="02/28/2010" Title="SPO2"
Details="Details Time Entry"/>
<igtl:DateTimeEntry Time="04/28/2010" Title="SPO2"
Details="Details Time Entry"/>
<igtl:DateTimeEntry Time="07/28/2010" Title="SPO2"
Details="Details Time Entry"/>
</igtl:DateTimeSeries.Entries>
</igtl:DateTimeSeries>
</igtl:XamTimeline.Series>

<!-- Set the timeline axis properties to months -->
<igtl:XamTimeline.Axis>
<igtl:DateTimeAxis AutoRange="True" UnitType="Months" Unit="0"/>
```

```
</igtl:XamTimeline.Axis>
</igtl:XamTimeline>
</GroupBox>

<!—Add a groupbox to organize document viewer content in first row and second
column-->
<GroupBox Grid.Row="1" Grid.RowSpan="4" Grid.Column="2" Background="Gray"
Header="Document Viewer" FontWeight="Bold" FontSize="13">
<Image Source="C:\pacemaker.jpg" VerticalAlignment="Top"/>
</GroupBox>
</Grid>
</ScrollViewer>
</Window>
```

5.1.7 System specification using the information system

Minimum system requirement for users is access to the Internet via a PC. In order to display the timeline, the user needs to download the open source Silverlight. Recommended and tested web browsers are Firefox (3.6) or Internet Explorer (IE6 or newer).

5.1.8 Overview of tables included in the database

The tables within the Thoraxpasient MySQL database are developed by existence or creation of new content types in Drupal. The content types are viewed as tables in this context. Only tables related to content such as patient, medical record and standard patient information are drawn in the overview. The overview includes each table with its name and attributes and how the tables are related to each other.

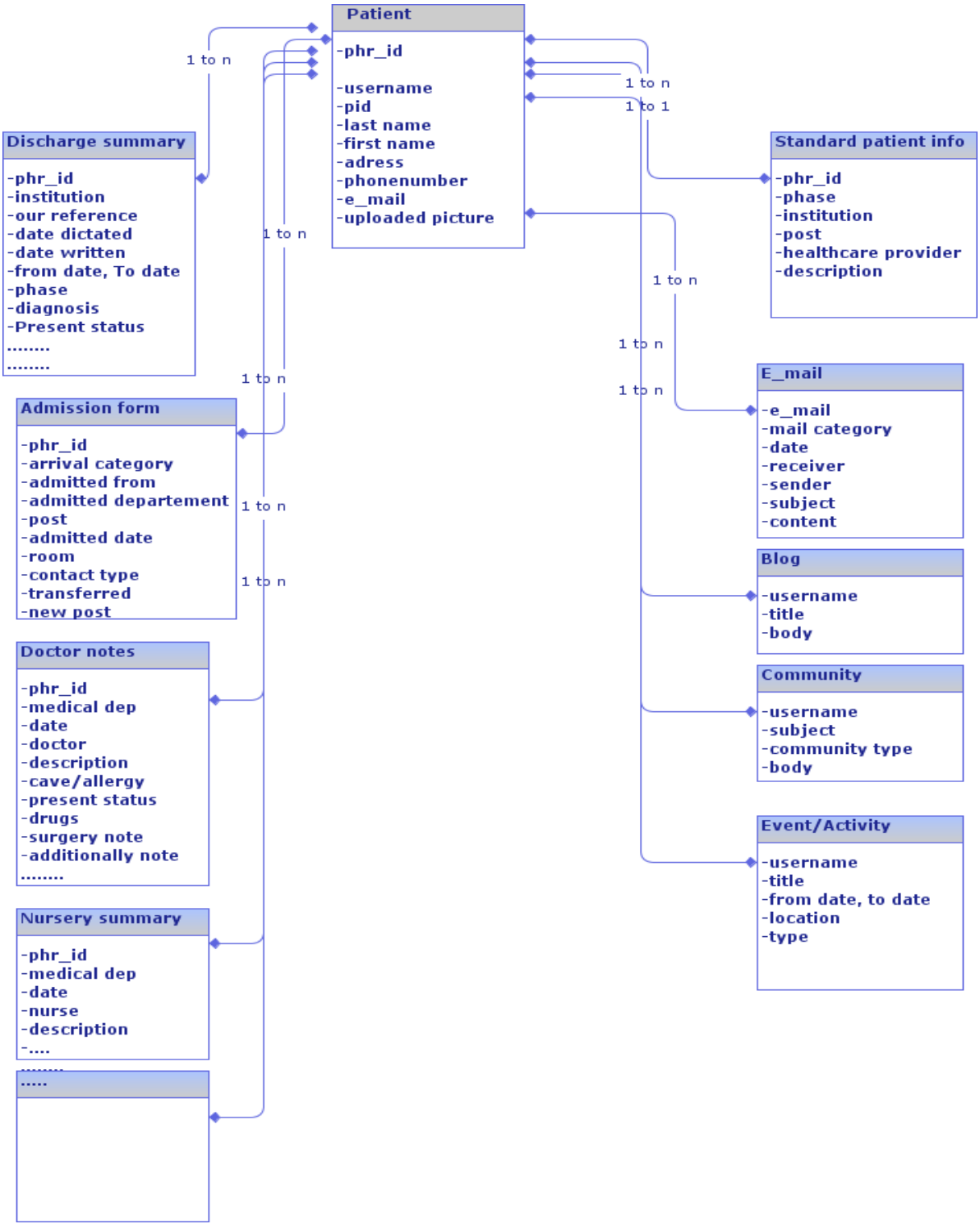


Figure 32: Overview of entity relationship diagram (ERD) included in MySQL database

6 DISCUSSION

The cultural historical review of the medical record indicates that the use of the record has changed over time, becoming a tool for a much larger user group than merely the doctors. The medical record has also developed in format, from being unstructured notes on single papers to becoming a more or less personal medical record managed and stored within electronic health record systems. Even the content of the medical records have changed; the written content is formulated in new ways, and new technology has contributed to the medical record with additional contents like x-ray pictures, ultrasound displays, monitoring diagrams, and more. Considering that it is over three decades since the Norwegian patients got the legal right to access (with few exceptions) own medical record, it seems rather strange that the development of PHR technology progressed at such a slow pace. Furthermore, few PHRs have been developed by user participation. In the last decade, however, several PHRs have been discussed and explained in literature. Close reading of these articles, however, reveals that the systems were not implemented. Current systems are either in their initial phases or on trial, and in this sense looks more like theoretical frameworks of PHR. However, based on movements in technical standardization and legal regulations in Norway, there is hope that the Coordination Reform may contribute to the implementation of an interoperable PHR in the near future. A note of caution is needed; experiences from other countries have shown that potential users do not necessary embrace these systems. Kahn and co-authors (2010) suggest that the slow adoption of PHR could be a result of "cost, access, and interoperability; security concerns; and data ownership". However, the authors suspect that the main reason for slow PHR adoption is associated with system design and implementation that potential users not find appropriate. Kahn and co-authors relate this to the lack of interoperability systems, and the fact that PHRs health information often have to be entered manually by the patients, which they find to be both "time-consuming and error-prone". The interesting question is: how patient controlled and patient owned could a PHR be, without making the system unreliable, and without questioning the system's validity? If patients obtain full control of the PHR, they may fail to update the PHR as often as is required from a health policy perspective, or the patients will insist on their own preferences for inclusion and exclusion of information in the PHR. Kahn et al (2010) assume that if patients do not have access to automatic aggregation of health information within their PHRs, they might abandon the systems since the health information will not be accurate and up to date. On the other side, if the system is clinically controlled and owned by a health enterprise, there will be challenges pertaining to the coordination of paper –based records and EHRs from a variety of healthcare entities; this

is so since the health care services in Norway have a fragmented health information system (HIS) structure. A clinically controlled PHR solution is therefore neither completely transparent nor will it be updated. Technical solutions to overcome an incompatible EHR should set priority for the health authorities, if the aim is to achieve an up to date and interoperable PHR.

Two PHR systems are discussed to illustrate the difficulty of getting users to adapt PHRs. These are Health eVet (a PHR for veterans in the US) and Health Space (a national PHR in United Kingdom). Both systems have large users groups; notwithstanding the limited interest that has been displayed. E.g. Health eVet is targeting 24 million veterans and 259 000 veterans staff, but only 850 000 of them has registered as PHR users (Nazi, 2010). The system includes patient health education information, a personal health journal, online refill of prescriptions and more. 30 million people have been invited to access the national summary care record and online health portal in England (Greenhalgh et al, 2010). The summary care record (SRC) consists of information about allergies, medication and adverse reactions. Patients still not included in the SCR trial project has to enter own health information in the online PHR, in addition to this they may manage healthcare appointments. The evaluation report of SCR and Health Space (PHR name) use and outcome reveals that patients have less interest in, or perceived benefits from the supposedly SCR that is supposedly "shared" between themselves and healthcare institution / providers (Greenhalgh et al, 2010). Greenhalgh and co-authors argue that the reason is that the SRC is often not available in clinics or hospital, since computer systems are incompatible. Thus, the evaluation includes findings about the medical records not being up to date, and sometimes not even available. None of these information systems seem to be developed with user involvement. A natural thing is for researchers following the implementation to start asking users what they would find useful and not within the PHR. It seems that system developers up until now simply have created a system that they *think* the users want, in opposite what users say about their actual needs. Schmidt and Bannon (1992) discuss the phenomena "appropriate the technology", which refers to users interacting with the technology in a different manner than was initially planned for or foreseen. Hopefully, user involvement can contribute to improved design of IT systems, and make the system users committed to its constructive nature.

In this study two prior patients participated in the PHR design. I learnt that the participants were not merely interested in common PHR content, e.g. they graded vaccine overview and

sharing medical record with relatives as “not so useful”. Even if they regarded the medical history as “very useful” within the PHR, none of the participants found support in the medical histories during problematic trajectories. However, I found that the participants had different health information needs, at different time and location, during the thoracic surgery process. The participants recognized the thoracic surgery trajectory and its phases as a useful way to organize health information. Therefore, I used the standard surgery trajectory as a framework in the further analysis, where I mapped the participants’ activities to better understand their actions in the context in which they were performed. When a patient is scheduled for thoracic surgery, several healthcare institutions are involved in this process. Therefore, patients need to be supported with accurate health information during the whole trajectory, not only the in the thoracic surgery phase. My results make clear that the participants perform a number of well motivated health information activities as patients, to achieve accurate and timely information. Their intentionality varies from activity to activity, and could be accounting e.g. for variations in decisions making, quality assurance, updated knowledge, possible patient complains, or mental preparedness before specific procedure / consultation with more. The participants were not particularly interested in the medical record in itself, since they reported that they did not find what they were looking for there. Instead they wanted additional information that could tell them what was likely to happen in the next phase of the trajectory, rather than just reading about what had happened in the previous phase or in the previous meeting with the healthcare provider. When I started this study, my main concern was how to present the medical record content to patients in a helpful and structured manner. I understood that the patients’ activities were complex; patients were doing patients work - and the interesting question became how to support this work with valuable information. Furthermore, I realized that access to the medical record was not supportive of all their activities. The EHR content is often not available to patients before being discharged from hospitalization. Though, the medical record content is considered useful in a retrospective perspective, the participants requested access to comprehensive information already during the initial phase of the patient trajectory. In Denmark, the medical record content is delayed with 14 days to make sure patients do not get critical information before healthcare providers have communicated the information verbally (Sunnhed.dk, 2011). Delay of access might be an issue in Norway as well. Furthermore, the way the medical record is currently organized did not impress the participants (or me). The information is unstructured and messy. Patients with severe illness often have frequent stays in hospitals, and these stays generate an amount of medical record content. The larger the medical record gets, the harder it is to navigate

through it. Every field of professionals working in the hospital have their own dedicated area within the medical record. This is practical if the patients are looking for specific information connected to a specific group of professionals, like for instance the nursery summary. However, upgrading the medical record to be something more than just a working tool for healthcare providers, raise a need for its information structure to change or to be adjusted to fit requirements and demands from patient groups as well. The participants acknowledge that information should be added to the medical record. They reported that they had experienced a lack of practical and standard information during the trajectory. As the individual activities were sorted and mapped in the trajectory timeline, the participants revealed that information was missing, or that they were getting misleading standard patient information. They were seeking an extended information package for the thoracic surgery trajectory. Both participants argued that they were missing information in the early entry phase of the thoracic surgery trajectory. Both had negative experiences caused by fragmented health information as a result of fragmented healthcare services. As soon as a GP or other specialist suspects that the patient might suffer from potential heart failure, the person should be given access to a number of information sources. First of all a comprehensive package of information related to the thoracic surgery trajectory should be made accessible to the patient. The trajectory package could be similar to the one offered by the Danish health care services; supporting patients during cancer trajectories. Implementation of PHR could contribute to the patients knowledge situation with a health information system that consist of all the (currently fragmented) health information pieces gathered from the different healthcare institutions involved in the thoracic surgery trajectory. According to the participants in this study, the information should be divided by time and connected to the specific time interval within the trajectory. Access to the standard trajectory and its phases could provide patients with knowledge in a manner similar to that of a reference value in a lab test. E.g. the participants recognized the standardized patient trajectory as comparable to own trajectory. However, their minor adjustments were explained by events that made it necessary to adjust the course. They both had a major interest in viewing the standard trajectory, and found it useful when mapping activities and identifying information sources. They also had an idea of making the step by step trajectory in a paper-based format to have a compatible format to access during the hospitalization stay.

The participant's interests in monitoring own health during the follow up phase varied. Their needs were identified as the outcome of aortic valve tissue material and use of pacemaker respectively. E.g. the participant with the mechanical aortic valve put in a lot of effort to

manage the dosage of the blood diluting drug. She therefore requested an overview of this medications dosage over time, and the ability to measure the INR with home equipment. In addition, she said that she did not have any benefits from monitoring her heart activity, since the pacemaker made her heart rhythm stable. The other participant, with no pacemaker, was troubled by high blood pressure, so he found it useful to monitor this object, preferably with home equipment.

Both participants reported that they often felt that calling the hospital was regarded as troublesome by the healthcare providers. This problem could be alleviated by support of social interactions e.g. secure e-mail that might strengthen the patient – healthcare provider relationship, and lower the barriers of asking questions. In addition, patient-to-patient interaction could profit from a common social network, to facilitate the asking of questions, and the exchange of knowledge - and patient experiences. None of the participants remember to have seen the patient's own report schema that addresses questions needing answers ahead of surgery. The report schema is important, as it includes questions about allergies (cave), medication, medical history, and more. This standard schema should be exchanged via the PHR. By doing so, the patients would be able to get hold of the schema in time, and the healthcare provider could rest more assured that the patient is being supported with available health documentation for accurate reply on the schema.

Another issue that needs to be addressed is how much information that has to be applied in the new information system, in order for patients to be satisfied and supported during activities. Is it actually possible to make sure that patients are supported by *enough* information, e.g. ahead of decision making, by implementing new technology? Feldman & March (1981) discuss this issue in the paper *Information in organization as symbol and signals.* They refer to Luce & Raiffa (1957) and Taylor (1975) in their definition of decisions: as "*decisions are seen as derived from an estimate of uncertain consequences of possible actions and an estimate of uncertain future preferences for those consequences"*. Feldman and March (1981) further say that none of these estimates are good estimates since they are based upon "*imperfect information"*. The authors' position is that a number of organizations and individuals will gather more information than they use in decision making. Simultaneously, their information need is usually infinite, they either ask for more information or make complains about lack of accurate and timely information. Feldman and March (1981) acknowledge that only information that might influence the decision making

has value, and that organizations / individuals have a tendency to collect information that are lacking in value. According to the authors, organizations, as well as individuals, spend time gathering more information rather than follow the decision making through, by supporting past choices. In addition, Feldman & March refer to findings about various aspects that influence the instrumental use of information in organizations. Their findings could be used improve our understanding of when new technology might be constructive and beneficial for both patients and healthcare providers. According to the authors, there are reasons to believe that there is "*positive incentives for underestimating the costs of information in relation to the benefits*". This is an interesting proposition in the patient – healthcare provider context, since the giving patient enough information may conflict with actually performing high quality healthcare services. The surgeons have limited time to provide patients with extensive information ahead of surgery. Patients are commonly sent to the regional hospital one or two days prior to the scheduled surgery. To satisfy the most information needy patients, the surgeons could probably lecture the patients for days to actually service their information need. But then surgeons would have less time doing surgery, and surgeon time is a scarce and valuable resource. So fully serving the (perceived) needs of patients for being (fully) informed would not be an efficient use of scarce health resources. According to Feldman & March (1981) too much information is not constructive either, since "*.... having too much information i.e., having an information overload increases the risk of being unable either to comprehend the information or to use it effectively in a decision. Since the information-gathering functions are typically separated from the information-using functions of organizations, incentives are modest for gatherers to avoid overloading users. The user of information invites a bias by accepting responsibility for the utilization of information while delegating responsibility for its available."*

How much information should we expect surgeons to give to their patients? If the surgeons were able to give pro and con information adjusted to the individual patients, together with expected prognosis and risks involved, patients would probably be satisfied. If the patient gets to little or too much information, he or she might consider cancelling or postponing the surgery. As a result, the scheduled surgery list will be shorted and available resources will not be put in to productive work. In the ideal case, were the patients get valuable information before and after the surgery, they might be able to prepare better and engage in activities that could make them go through the trajectory and improve their recovery following surgery. However, the balance of giving the patients enough and valuable information is no easy task.

Secondly, the authors' claim that information is most often collected in surveillance mode, and to a lesser extent in decision making mode. This claim might hold for thoracic surgery patients as well, since their goal orientated activities are motivated by more than decision making, and include aspects such as mental preparation, acquiring knowledge, assuring quality, and more. In this relation, patients seem preoccupied by seeking out information that includes type of surgery, thoracic surgery trajectory, prognosis, the cause behind the surgery, and more. In addition, they probably make their decisions in close dialogue with their healthcare providers, and are therefore likely to spend less time gathering information for decision making (as opposed to surveillance) from additional information sources.

Last, Feldman and March (1981) state that information is often a "*subject to strategic misrepresentation*". When patients only use their healthcare provider as an information source ahead of decision making, the patients are trusting and depending on their provider as the sole and neutral provider of knowledge. Though, the healthcare provider may be influenced by his or hers institution work practice, skills or limitation. If the healthcare provider knew that in another hospital the surgeon or clinical procedures produced a superior outcome, would s/he tell the patients? Similarly, it might be easier to focus on information that includes potential positive outcomes compared to the potential risks involved. Healthcare institutions are also constrained by scarce health resources that affect the healthcare services provided. Likewise, information given to patients might be limited to options that have costs that the institution can afford, or services that might increase their performance because they are prioritised in the Diagnostic Related Groups (DRG).

Feldman & March (1981) are referring to acknowledgement made in the classical decision-theory such as *"Investments in information are made up to the point at which marginal expected cost equals marginal expected return...."*. Their own findings do not corroborate the above theory, as they state that "*Individuals and organizations invest in information and information systems, but their investments do not seem to make decision-theory sense. Organizational participants seem to find value in information that has no great decision relevance. They gather information and do not use it. They ask for reports and do not read them. They act first and receive requested information later."*

This might be the case for some patients as well. They are given the paper based patient summary / discharge note short time after becoming an outpatient, but might not read it before symptoms or problems appear.

So how could the new information system contribute with patient information that is likely to have value? First of all, the system has to supply patients with comprehensive information (medical record and standard patient information) as a whole, regardless of time and place. This is in contrast to the current informational regime, in which the institutions' information seems fragmented and contingent on both time and place. However, the system requires that substantial information resources are released from all involved healthcare providers and institutions. It is healthcare providers and institutions that have to generate accurate and timely information, piece by piece, for the patients to get the big picture. Each institution patient's information is sewed together and displayed to the user in the trajectory's phase it belongs in, viewable in the proposed information visualization (timeline view). The provided information is to some extend individual, as it includes patient specific information - like information adjusted with regard to type of surgery, medical record content, healthcare scheduled activities and more. The written content in the medical record cannot be comprehended by all (or most) patients, even with a dictionary or other supportive features (like reference values to lab tests). For this reason, the standard patient information is useful to make sure information is written in a lay person's manner and is understandable to the audience. The information has to be accessible to patients in initial entry of the trajectory to assure timely information, and as the patient traverses the phases in the trajectory, the institutions included have to send standard patient information to the patient's PHR as soon as possible. In this way patients will get virtual access to information before physically entering the healthcare institution. These suggestions will probably not fulfil the information needs of all thoracic surgery patients, but will furnish patients with more complete and timely information. Hopefully, the proposed information system will support the patients with information of greater value than currently. In the future patients are likely to get additional access to dedicated decision making tools that will enable them to make better use of available information.

It should be emphasized that the new technology proposed, will supplement to face-to-face communication, not replace it. The system makes a contribution to timely access to relevant information, and available access to information that for some reason is not shared during the

regular patient – healthcare provider consultations. As the participants told their own patient stories and as they share their experiences in meetings with other patients during their trajectory – the need to know varies from patient to patient. E.g. the participant who encountered major challenges in order to get accurate and timely information for decision making ahead of surgery, was surprised when he met another aortic valve replacement patient that did not know which type of tissue her new valve was made of. Some patients are comfortable with the choices made by their healthcare providers, and takes limited interest in surgery details. Others have substantial interest in playing an active part during the healthcare treatment, and mediate with the healthcare provider during the thoracic surgery process. For the latter group of patients, the new technology may be of great importance and support. In one participant's formulation: "I will play an active part in healthcare situations, to make sure that I am comfortable with the outcome. Since risks and consequences are too late to argue about in the end of the trajectory. I will not be a person that just say later that the doctors did this to me and they never told me that this could be the outcome"

An aspect that has not been given much attention in this report is the participants' willingness and interest in making contribution by joining research studies. Both participants give the PHR features "Participate in research studies" the highest possible score. The PHR could be a canal for researchers to recruit potential participants for relevant thoracic surgery studies, and to carry out surveys in larger and / or specific patient group. Use of medical records in quality studies or in research is common in medical studies. However, fragmented medical records do not give a complete picture of the patients. Healthcare providers at the regional hospitals most likely have institution-specific, and research relevant, information stored on included patients. Thus, participants by use of PHR could report additional information. Examples that come to mind is the use of PHR when reporting problems and symptoms appearing after surgery; in connection with a prescribed drug; online monitoring of subjects of interest by use of home equipment; and more. This collecting research data may also improve the quality of healthcare service, since feedback from patients could be used to adjust tomorrow's healthcare services.

6.1 Challenges

6.1.1 Sick persons and participatory design

A critical aspect of this study was to get patients to participate. The challenge is that patients tend to be 'busy' and unable to prepare due to upcoming surgery; in a bad health condition, or knocked out by medication in post- surgery. The population under study may not be motivated for a comprehensive user – centred design project. This is especially so, since not all patients have asked for the system in the first place. An additional challenge revealed by this study, is that healthcare professionals were caring protecting with respect to their patients, and tried to shield them from disturbances beyond the necessary. The explanation for this is that the patients are in serious health problems and will undergo surgery. The thoracic surgeons, as well as the nurses do not like to be disturbed in their busy working environment with questions or requests not directly related to producing a good outcome for the patient in question. Therefore, in the initial phases of this study – the lack of voluntary participants required substantial announcement activities to approach and recruit relevant patients. However, even patients that agreed to participate were not always available, since their condition and / or treatment were hard to predict, and often dictated a drop-out from the sample. In addition, to get in touch with the patient after hospitalization requires substantial resources, since the patients at Oslo university hospital are supplied from all health regions in Norway. Thus, patients undergoing surgery at the regional hospital are on average in a worse condition than patients receiving treatment at local hospitals (so there is a selection problem lurking underneath). To find suitable and willing patients that were interested in design, familiar with handling personal services online and were living in south-eastern Norway, was not an easy task. In the initial phase of this study, the plan was to go behind the scene in the thoracic surgery department and be a passive observer to the information flows between patients – surgeons; patients – nurses; and nurses – surgeons. But after a voluminous email correspondence, and two meetings with the thoracic surgery department, one realized that the healthcare professionals were too protective of their patients during hospitalization for passive observation to succeed. Since Oslo university hospital – Rikshospitalet is a regional hospital, patients either come one day prior to scheduled surgery, or even at the scheduled day. After surgery they are transferred back to their local hospital after discharge from post operative care. As a consequence only pre – or post thoracic surgery patients were invited to participate in the study. In addition, the real time pre – and post surgery period is not observed. Thus, patients that are invited to participate while being hospitalized are either patients undergoing

controls before planned surgery, or patients undergoing controls a set time period after surgery. These circumstances placed limits on the investigation in this thesis. Prospective or retrospective reports from patients were considered, direct observations during hospitalization was excluded. The gathered information is therefore either based on patient's memories during past hospitalization, or on information that patients conjecture will be relevant and valuable in future scheduled hospitalizations.

Collaboration with thoracic surgery patients needs to be carried out with care and respect. It must be remembered that such participants have been or is currently in a possibly life-threatening situation. This may cause a new perspective of life all together, or even guilt in some cases (were bad life habits indirectly has caused the illness) One has to expect patients / design partners to be more emotional than normally. In addition, the design partner should not be disturbed more than strictly necessary. To prevent stressing patients with demands and expectations, there is a need for planning and structure of meetings. During meetings for interviews and prototype evaluation, one should ask the participants for short breaks to avoid exhaustion of the patient. If patients with physical disabilities are included in design studies, one should take this fully into consideration and find alternative ways to access the web based PHR, e.g. by use of voice only or touch screen. Alternative way of accessing information has not been taken into consideration in this study, due to limited resources.

6.1.1 Recall bias

A key limitation to the present study needs to be addressed. It is the retrospective reporting of patients' activities. In many ways it would be preferable to use direct observations of the patients as they traverse the trajectory. However, this is not considered possible, since it would require the researcher to follow patients around at home, to register how they perform their health information activities. Within the regional hospital it is not possible to observe in this way either, since patients enter at most a day prior to surgery, and do not spend time recovering in Rikshospitalet but are transferred back to their local hospital after they are released from the intensive care unit. Thus, the time period spend at Rikshospitalet does not include much of the pre- and post-surgery work that we are interested in observing. I am left with the participants' memories, and perhaps the memories of their significant others to inform the design.

6.1.2 Use of theory limitation

Use of activity theory in system design has also imposed limitations, since it restricted the number of participants it was feasible to include in the study. The patients' health information activities during the thoracic surgery timeline generate a high number of activities. If ten or more participants were recruited, this would most likely have produced an overload of health information activities – even after grouping similar such activities together.. Scarcity of resources, and practical challenges with the design led us to consider two participants enough.. With only two participants the research design of necessity became quite intensive. Nonetheless, it is important to underline that the stories told by the participants are not representative for the typical thoracic surgery patients. The participants are self-selected as they responded to positively to the recruitment. They both said that they wanted to contribute to science, and that they hoped that by sharing their stories they might help future patients in similar situations to improve their information flow.

During the initial interviews the collected information was re-organized by concepts and components taken from the activity system model, based on Engeström's extended version of CHAT. I have made three additions to Engeström's components: namely intentionality, original information source and design consideration. The reason is that I needed these essential components to induce a clearer emphasize on the design issues relevant in my study. I found the proposed and extended framework highly useful in the design process. The identified activities were sorted and mapped vertically by information source, and horizontally by trajectory phase. The information source was categorized as EHR related information, verbal information (typically gained during conversation between patient and healthcare provider) and additional standard patient information such as brochure or forms. During the second interview with the participants I was able to adjust and quality check the individual mapped activities, to make sure I had understood the gathered information properly. Based on these recognized activities, I was able to make design suggestions of potential features that should be included in the future PHR. My design suggestions were built on five sources of gathered information and evaluation: 1) existing features within beta realized or planned PHR 2) the participators health information need based on their recognized activities 3) the participants health service needs, such as monitoring from home and collecting measurements for use during healthcare consultation/ follow ups 4) paper-based prototypes displayed to the participants 5) experimental design of timelines overview and content.

7 CONCLUSION

7.1 Conclusion

Findings in the study indicate that patients' need different information, at different times during the thoracic surgery process. Their information need is not only about access to medical record content, with additional features to understand the records content. The participants experienced a strong need for prospective information, like standard patient information accessible during the thoracic surgery trajectory. Especially, they requested access to information in the initial entry phase of the thoracic surgery trajectory. Their information need were associated with lacking information - based on activities' with different motives; e.g. mental preparedness, quality assurance, knowledge, decision making, and more. I have found use of the standard thoracic surgery trajectory helpful as a framework to understand and support the patients' activities. Thus, the proposed technology includes access to relevant health information in a time line associated to phases within the trajectory. This should better support patients' activities with accurate and timely information. Both participants reported negative experiences with fragmented health information, as a result of traversing the fragmented healthcare system. New technology will hopefully contribute to the merging of relevant information pieces from the various healthcare providers and institutions that are involved. Thus, the proposed PHR could be an information system for standardized patient trajectory, designed to support and coordinate care for thoracic surgery patients.

7.2 Further work

The proposed information system is a prototype that needs to be further developed before testing the user interface on potential thoracic surgery patients. However, the system could be implemented with only standard patient information in a trial period. This should limit the challenges with privacy policy, and reduce the sensitiveness of the system's information content. The system should then be tested as a shared information space for patients and healthcare providers. This exchange requires secure information, by use of The Norwegian Health Network. It would be of great interest to test the system with real patients in their complete trajectory, from the initial entry of the thoracic surgery trajectory until the end of the trajectory. The identified standard patient trajectory makes it easy to add patient data for further analysis, including identifying activities, mapping activities and redesigning the thoraxpasient.com. Thus, the system-feature and design could be adjusted to increase the user experience for a larger group of thoracic surgery patients, and to make the system more

robust. Thus, it is recommended to approach the study with similar methodology as describe in this project.

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